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Monitoring everyday life in aging & dementia

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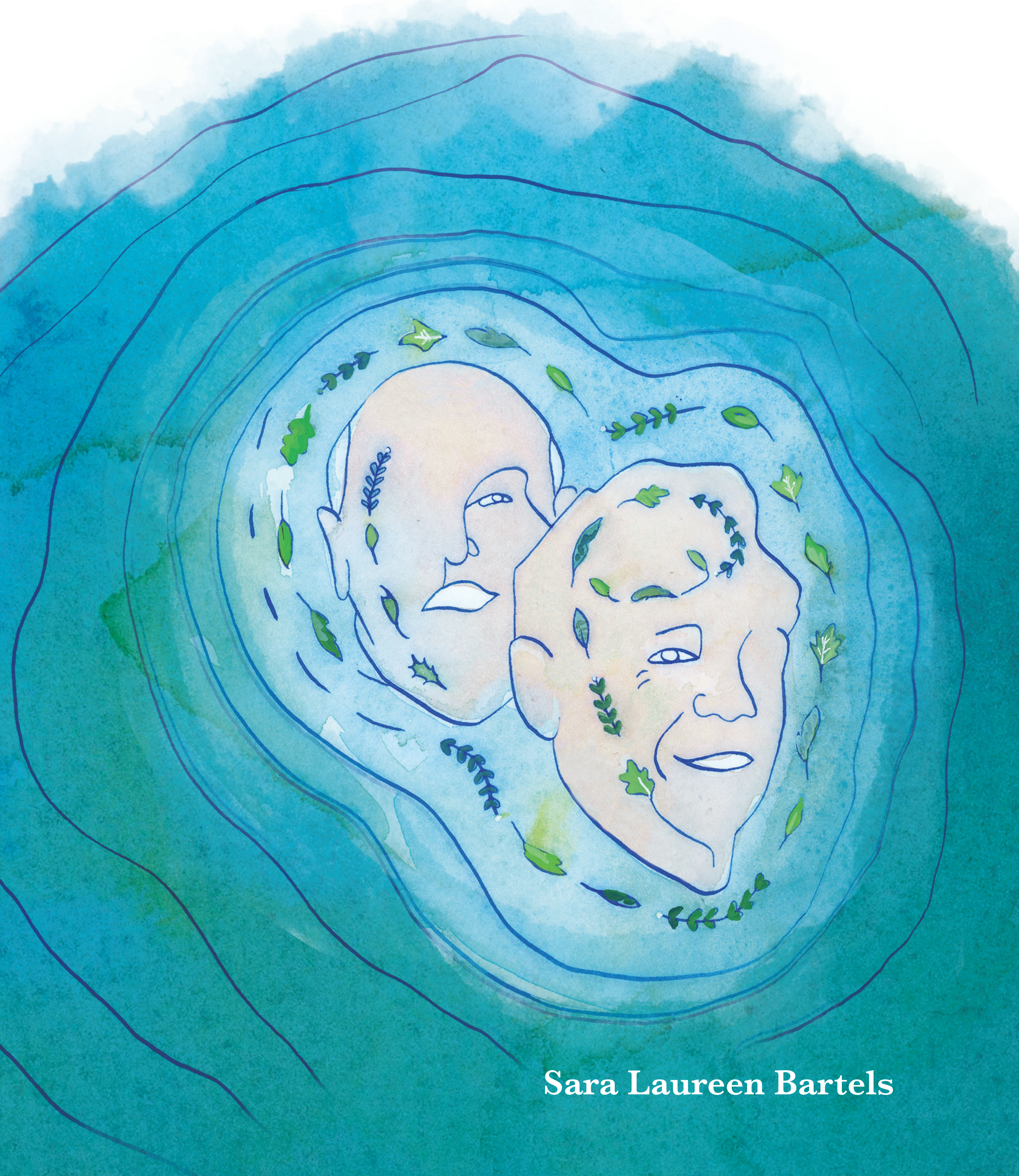
Perspectives from Experience Sampling and Technology Use



Sara Laureen Bartels

Monitoring Everyday Life in Aging & Dementia

Perspectives from Experience Sampling and Technology Use

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Monitoring Everyday Life in Aging & Dementia

Perspectives from Experience Sampling and Technology Use

Dissertation

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by

Sara Laureen Bartels

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Declaration of competing interests

For most Chapters, none of the authors have any disclosures to report. The authors of Chapter 5 declare the following financial/personal relationship, which may be considered competing interests: Intellectual Property Rights remain with Prof. Dr. Philippe Delespaul and the Department of Psychiatry and Neuropsychology at the University of Maastricht. To ascertain scientific integrity, the researchers have renounced all (actual and future) financial benefits.

The research described in this thesis was performed at the Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Maastricht University, Alzheimer Centre Limburg, Maastricht, The Netherlands. Printing of this thesis was kindly supported by Maastricht University.

In memoriam Opa Walter & Opa Heini

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Chapter 1

General Introduction

Health & aging

Health can be described as the ability to self-manage and adapt to physical, mental, and social challenges [1]. In everyday life, feeling healthy may include experiencing happiness and having a purpose, being able to take the bus to see a friend, or managing pain through exercising. During aging, the interrelatedness of the different health aspects is clearly visible in this reflection from an older person:

"It all starts with psychological well-being, doesn't it? That kind of rules out feeling lonely and you probably would be mobile as well. If you feel well, you are better able to care for others. These themes all connect to each other." [2]

In the present aging society, a great number of individuals face complex and multi-layered health challenges. An older person may be affected by one or more health issue him/herself or be required to support someone living with a condition. As age is the main risk factor for cognitive disorders [3], older adults may need to adjust to a life with mild cognitive impairments (MCI) or dementia. MCI is thought to not impact daily functioning greatly [4], however, even small cognitive alterations can influence an individual's health and everyday life including changes in feelings, behaviours, self-perception, or social interactions [5]. A neurodegenerative disease such as dementia results inevitably in the need for daily support. Commonly, this support is provided by the spouse or another family member [6]. However, caring for a person with dementia impacts the carer's physical and mental well-being [7, 8] and carer distress may in return affect the well-being of the care recipient [9]. As described, it is crucial to understand the complexity of daily challenges, experiences, and patterns of older adults and, thus, be able to support them in managing their physical, mental, and social health in everyday life.

Traditional methods to understand everyday life

One common method to gain insight into health aspects of an individual are questionnaires relying on *self-reports*, where an individual answers questions often retrospectively. For example, the Hospital Anxiety and Depression Scale (HADS), instructs individuals to rate how they felt in the past week by rating a question like 'I feel cheerful' with answer options ranging from 3 (not at all) to 0 (most of the time) [10]. The HADS, among other self-reports, is widely applied and provides a reliable and generally valid subjective perspective [11]. One should consider, however, that a memory bias can influence the answers as it is difficult to accurately reflect on past emotions and individuals tend to over- or underreport [12]. Additionally, self-reports have been discussed to be of limited real-world value and may therefore lack ecological validity [13].

Reports from proxies, such as a partner or close friend, may add to self-reports when one wishes to get an external perspective or in cases where the individual is unable to provide a self-report in the first place. In the diagnostic process at memory clinics, proxy reports are an important element of the procedure [14]. Unfortunately, proxy-reports face the same dilemma of retrospectivity and memory-bias. Strong emotions, such as feeling burdened as a carer [15], or limited insights into another person's feelings may contort the accuracy of proxy-reports. Generally, scores of proxy- and self-reports may deviate from each other, particularly in people with memory problems, with proxies potentially rating symptoms or daily difficulties as more severe [16]. These findings highlight the need to combine different retrospective methods.

When assessing human cognition specifically, *neuropsychological assessments* can be applied. These assessments are a relevant pillar in neurology, neuropsychology, and psychiatry and can distinguish normal cognitive functioning from impaired cognition [17]. However, assessments of cognitive functioning take place periodically every half year or even year. Thus, these tests neglect daily or situational fluctuations and portray a rather temporary picture. The ecological validity of neuropsychological assessments is also questioned as clinical settings are calmer and have less interfering stimuli than the real world [18]. While this method may be suitable for diagnostics, limitations appear particularly when aiming to capture dynamics of cognition in natural environments or to understand interferences of cognition on daily functioning.

Finally, *observations* can be performed to examine an individual. Very detailed information gets extracted from observations and this approach does not rely on memory as reflective notes are usually taken during the observation itself. Nevertheless, the interpretation of the observations depends on the observer [19, 20] and, therefore, mainly the overt can be captured and subjective feelings may be missing. Furthermore, the insight from this real-life approach is limited to the number of observations made. As health and everyday life is complex, one or two observations cannot reflect the variety of daily experiences in its entirety. In summary, even though traditional methods offer valuable insights into various daily aspects, the challenge persists to apply a method that monitors and captures the dynamics and complexity of everyday life even better.

The Experience Sampling Method

The experience sampling method (ESM) is a diary method enabling individuals to provide self-reports on own emotions, activities, and context in the moment they occur [21]. Therefore, this method is not affected by a memory bias and has a high ecological validity [22]. As the person fills in short questionnaires repeatedly throughout the day, the ESM also depicts complex patterns and reflects on individual fluctuations within- and between days [23]. Traditionally, paper-based diaries were used to collect information throughout the day. Nowadays, new technological solutions for ESM use are available including personal digital assistants (PDAs) or smartphone apps [24]. The ESM has been used in psychiatry and beyond to study specific patterns, relations, or networks [25]. Within psychosocial interventions, the ESM can also be used to facilitate daily self-monitoring, thus raising awareness for own emotions and behaviours, increasing well-being, or promoting a behavioural change towards a healthier lifestyle [22, 26].

In the field of aging, dementia, and care, the ESM has been used in a small number of studies. For instance, research shows that the applicability of the ESM in family carers of people with dementia is feasible [27], useful to understand daily patterns [28, 29], and can even improve carer's well-being within an intervention approach [30]. ESM studies seem to include some elderly populations [31, 32] or middle-aged cognitively impaired individuals [33, 34], but rarely older adults with cognitive impairments. These studies are a promising start, however, the potential of monitoring the various facets of everyday life though technology-based ESM in the elderly needs to be critically evaluated to refine the method and ultimately improve health in older adults with and without cognitive impairments or dementia.

Everyday technology and eHealth in aging

In our daily lives, technologies are omnipresent. The term everyday technology (ET) includes technological items and services, ranging from washing machines, to smartphones, to ticket machines at train stations [35]. When technologies and the internet aim to support health, these innovations are referred to as 'eHealth' [36].

On one hand, older adults see benefits in using technologies and eHealth, for example, to facilitate communication with peers or health care professionals [37], or increase the understanding and ability to self-monitor own medical conditions [38]. On the other hand, technology use may be experienced as stressful, challenging, or even excluding, particularly by elderly populations or people with cognitive impairments [39]. The ability of older adults with and without cognitive impairments to use ETs needs close attention and different methodologies aiming to study technology use may have their strength and limitations. Generally, the positive and negative impact of ETs should be kept in mind when selecting an eHealth approach, such as technology-based ESM, to provide services and improve health.

Research into eHealth has snowballed over the past years. Nevertheless, several open questions regarding eHealth and aging remain. These include methodological issues, the feasibility or usability of certain eHealth approaches, eHealth intervention designs and their effectiveness, as well as the implementation of eHealth into practice. When carefully evaluated and optimized, eHealth may offer unique opportunities to enhance the understanding of everyday life and health management support in various senior populations.

Thesis aim and outline

This thesis aims to improve the understanding of everyday life in older adults of different target groups with a special focus on cognitive and affective functioning and technology use. Methodologically, the ESM, self-reports, observations, as well as literature searches are used to describe a comprehensive picture. Questions target the feasibility, usability, and validity of tools, aspects related to interventions, and the implementation process. Depending on the specific research question, people with MCI or early-stage dementia, informal carers of people with dementia, or healthy individuals are included in the studies.

PART I: Feasibility & Usability

The first part of this thesis focuses on understanding the everyday life of older adults with cognitive impairments. Part I includes the general ability of older adults with MCI or dementia to use ETs, the feasibility and usability of technology-based ESM in people with MCI, and the development and testing of ESM-based cognition tasks.

1. *How does the self-perceived ability relate to the observable performance to use ETs in people with MCI or dementia?*
   As ETs are present in various daily situations and can impact functioning, **Chapter 2** evaluates the relationship between a self-perceived report and an observational tool assessing the perceived and observed ability to use ET in 41 people with MCI and 38 people with dementia.

Based on the results from Chapter 2, the next Chapter uses complementary traditional methods to study the ability of people with MCI to use the technology-based ESM.

2. *How feasible and useable is the ESM delivered through a smartphone app in people with MCI?*
   In **Chapter 3**, the feasibility of smartphone-based ESM in 21 people with MCI is determined through the compliance rate, participants' experience, as well as observations of the human-technology interaction. Furthermore, the usability of the ESM in this population is demonstrated on an individual- and group-level.

Cognition is an essential element of daily functioning, particularly in aging populations, and may fluctuate within and between days. Therefore, developing momentary assessment tools to capture cognition in real-life within a digital ESM tool is part of this thesis. The following two chapters focus on healthy adults to establish knowledge on the general feasibility, usability, and validity of momentary cognition tasks before the tasks might be used in more vulnerable patient populations in the future.

3. *Is it feasible to use a momentary cognition task within a digital experience sampling approach to capture cognitive performance in everyday life?*
   In **Chapter 4**, the momentary Digit Symbol Substitution Task (mDSST) within an ESM app is piloted in the general population. Outcome measures include the participants' experiences, compliance rate, and contextualization of the momentary cognitive performanc.

4. *How feasible and valid is the use of two momentary cognition tasks within the ESM and what lessons can be learned for the future development and use?*
   Chapter 5 extends the research question from Chapter 4 by using the momentary Visual Spatial Working Memory Task (mVSWMT) in addition to the mDSST within an ESM app in a broader general population. The feasibility and validity is examined and lessons-learned are drawn for future momentary task development and use.

Part II: Interventions & Effectiveness

The ESM can not only be used to understand everyday life, but also to improve well-being. Part II elaborates on the set-ups of such ESM self-monitoring interventions in a more general way, intervention mechanisms, and the sustainability of intervention effects. The latter two zoom in on an ESM-based intervention for spousal carers of people living with dementia.

1. *How are digital self-monitoring interventions for middle-aged and older adults composed and which elements should be considered for future interventions?*
   In **Chapter 6**, the literature is systematically reviewed to provide a comprehensive overview of interventions incorporating digital self-monitoring elements and intending to improve health in middle-aged and older adults. Elements that stand out are discussed and may be considered for prospective study designs.

2. *What are the mechanisms of the 'Partner in Sight' ESM-based intervention for spousal carers of people with dementia?*
   This is a secondary analysis of the 'Partner in Sight', that had previously shown to improve emotional well-being of carers[30]. While the previous randomized controlled trial evaluated the effectiveness using retrospective instruments, the present study investigates intervention mechanisms using momentary data. **Chapter 7** includes ESM data from 72 spousal carers and focusses on changes of daily activities, and their relation with affect and activity-related stress. Special attention is paid to the impact of personalized ESM-based feedback on the daily patterns.

3. *How sustainable are the positive effect of the 'Partner in Sight' intervention for spousal carers of people with dementia?*
   After the ESM-based 'Partner in Sight' intervention had shown to improve carers well-being post-intervention and at two-month follow, the six-months follow-up data of the self-same intervention is investigated in **Chapter 8** (n=50 spousal carers). Furthermore, the general necessity for sustainable intervention effects for informal carers of people living with dementia is emphasized.

PART III: Implementation

Next to the feasibility, usability, and effectiveness of eHealth tools and interventions, the implementation into practice should be evaluated. This aspects of the research process is taken into account in Part III with a focus on eHealth interventions for carers of people with dementia.

1. *What evidence exists on the topic of implementing eHealth interventions for carers of people with dementia and what determinants influence the successful implementation?*
   Chapter 9 systematically reviews the literature on the implementation of eHealth interventions for carers of people living with dementia and identifies determinants of successful implementation.

The main findings and implications of all chapters within this doctoral thesis are discussed in **Chapter 10**.

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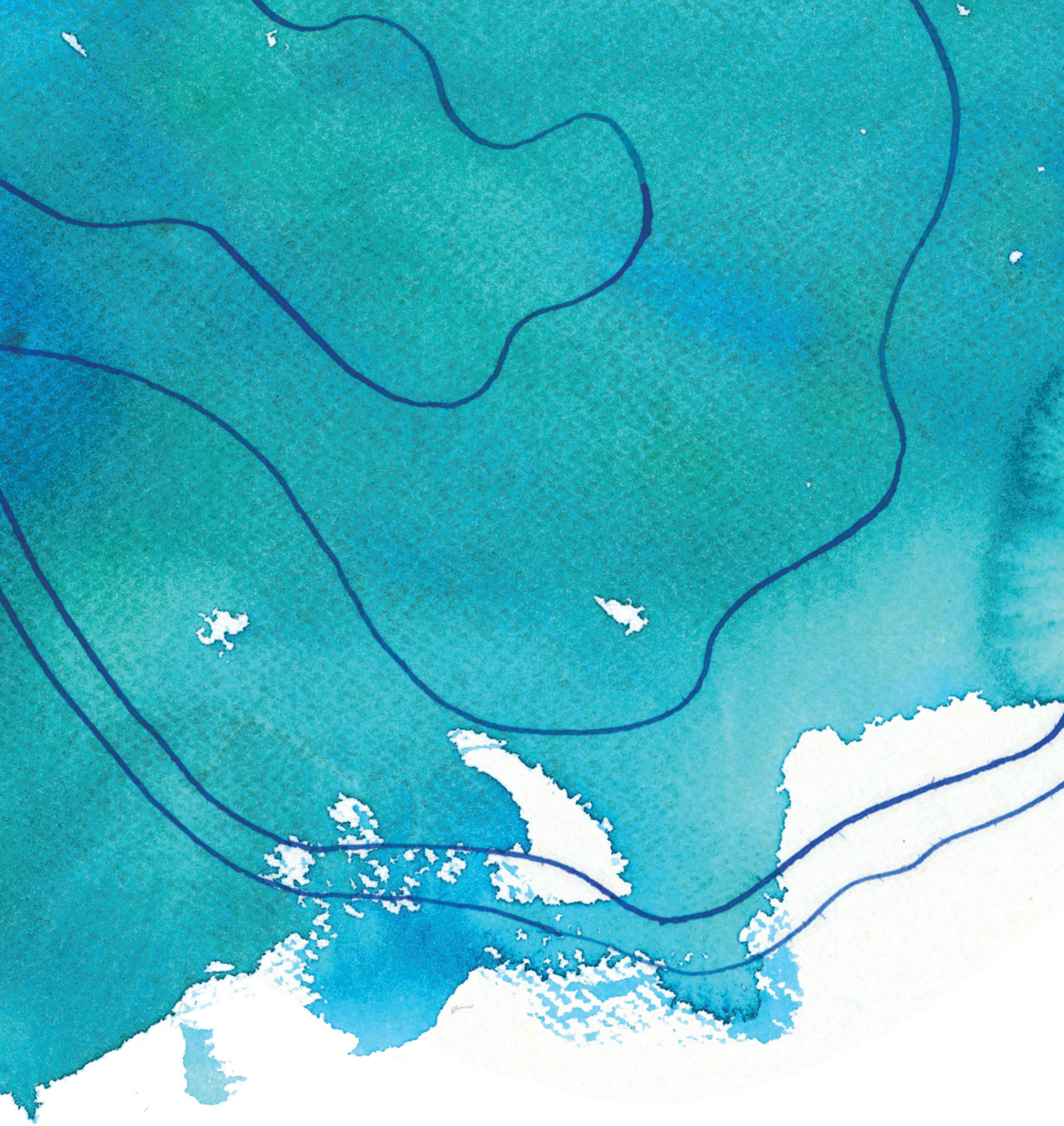
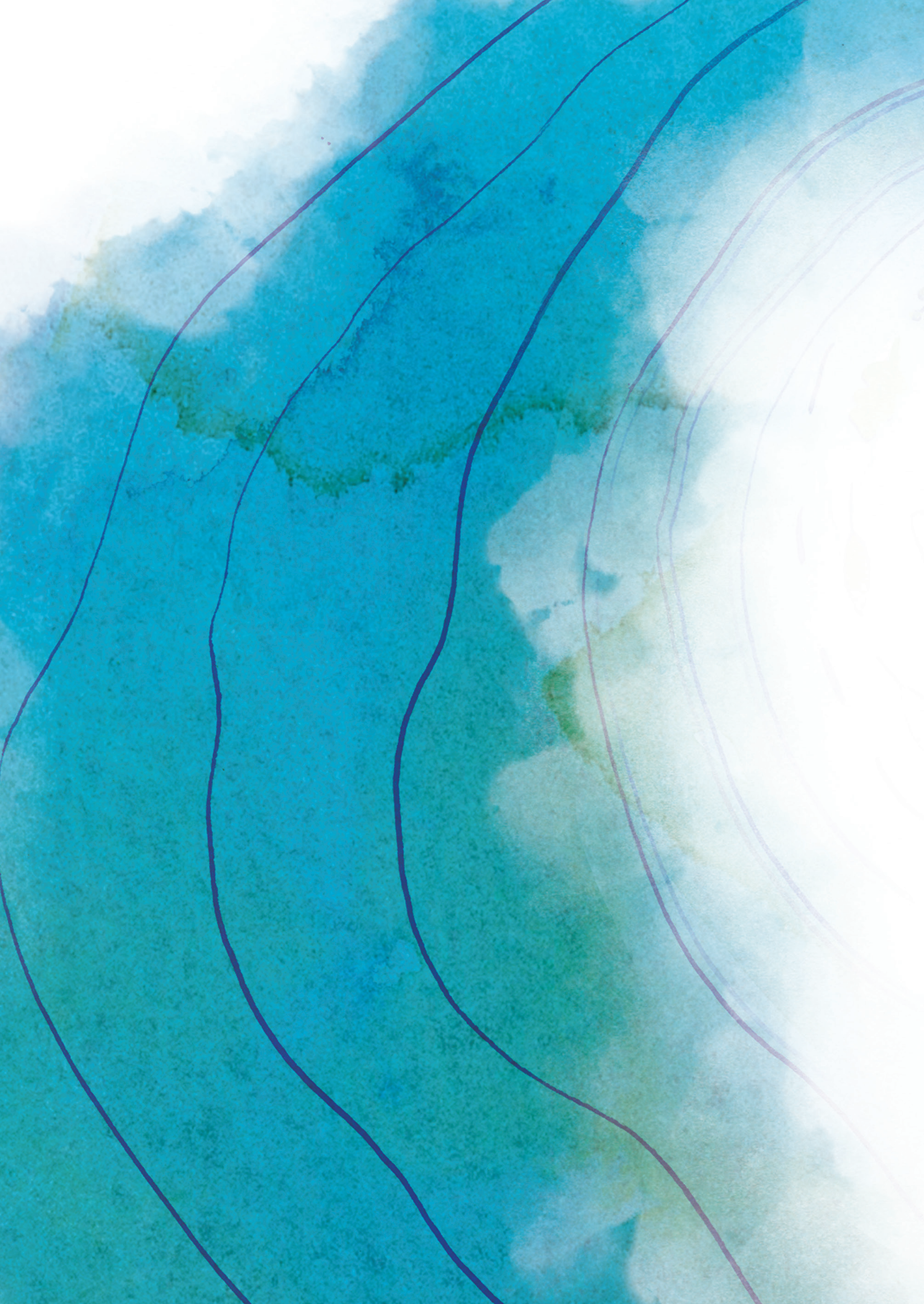


Part I

Feasibility & Usability



Chapter 2

Do You Observe What I Perceive? The Relationship Between Two Perspectives on the Ability of People with Cognitive Impairments to Use Everyday Technology

Sara Laureen Bartels, Sussi Assander, Ann-Helen Patomella, Jenny Jamnadas-Khoda, & Camilla Malinowsky.

Aging & Mental Health (2019)

Abstract

Objectives: Everyday technologies (ETs) can be challenging to use, particularly for older adults with cognitive impairments. This study evaluated the relationship between the self-perceived ability to use ET and observable performance of self-chosen and familiar, but challenging ETs in people with mild cognitive impairment (MCI) or dementia.

Method: A self-perceived report, the Everyday Technology Use Questionnaire (S-ETUQ), and a structured observational tool, the Management of Everyday Technology Assessment (META), assessing the perceived and observed ability to use ET, were used in 41 people with MCI and 38 people with dementia. Correlations were investigated with non-parametric statistical tests.

Results: In the dementia group, self-perceived report and observational scores correlated on a significant medium level (R_s=0.44, p=0.006). In the MCI group, no significant correlation was found.

Conclusion: The findings of this study suggest the ability of older adults with cognitive impairments to use ETs can be depicted with self-perceived reports as well as with observations. However, the combination of both approaches is recommended to get a comprehensive picture. While the S-ETUQ provides a broad picture of the use, presence and relevance of technologies in an individual's life, the META describes a specific human-technology interaction in detail. Furthermore, the results suggest people with early dementia retain the ability and insight to accurately reflect on their own ability to use ET, emphasizing the need to include their experiences in research and clinical work.

Introduction

As technological development continues to further influence everyday life [1-3], it is important to evaluate the ability to use technology and the effects this human-technology interaction can have on the elderly [4]. Technologies supporting older adults with and without disabilities have been reported to maintain or improve cognitive functioning, promote feelings of independence and safety, support social connectivity or increase well-being [5-8]. In contrast, the involvement of technology in daily activities has been described as potentially demotivating or misleading in the elderly population [9, 10], pointing out that technology can also complicate everyday life. A meta-analysis showed that age is negatively related to perceived ease of technology use [11] and technologies with greater complexity are more demanding for older compared to younger adults [12], which might indicate a greater challenge for elderly with cognitive impairments.

Structured self-reports are a common method to gain insight into individuals' self-perceived abilities. Various tools have been developed specifically for older adults and assessed with proven psychometrics for example instrumental activities of daily living [13]. The Everyday Technology Use Questionnaire (ETUQ) was developed to assess the ability of older adults to use everyday technology (ET). ET is here defined as all electronic, technological or mechanical equipment that exist in the everyday life of the individual, for example, smartphones, online banking, or remote controls [14]. ET thus describes a wide range of objects/services with a variety of complexity. The ETUQ structured interview evaluates the relevance of and perceived ability to use various technologies in an individuals' everyday life. The tool has been repeatedly used in older adults with and without cognitive impairment [15-18]. Guided by the ETUQ, participants are asked to ETs from various areas of everyday life such as home maintenance (e.g. coffee machine) or purchasing (e.g. ATM).

The ETUQ has shown to have a person reliability of 0.81 suggesting a high replicability in the generated measures [19]. Furthermore, the ability to use ETs seems to highly correlate with activities of daily living [20]. This highlights the necessity to take the ability to use ET into account when focusing on participation in everyday life. In the worst case, the inability to manage ETs could result, for example, in problems paying for services (e.g. transport) and resources (e.g. food) that influence well-being and health . In 2011, a short version of this assessment tool, the S-ETUQ, was developed reducing the amount of items from 90+ to 33 to provide a more convenient, cost-, and time-effective tool to investigate the ability to use ET in clinical practice with equally reliable person measures of perceived abilities [21].

In addition to self-reports, observations can be performed to evaluate an individuals' performance or ability. This might be particularly important when investigating people with MCI and dementia, as a lack of certain dimensions of insight has been described as increasing with disease severity [22]. The evaluation of own memory function and problems in activities of daily living seem particularly difficult for people with amnestic dysfunctions [23], which might affect the outcome of self-reports. However, to this point it is unclear how accurate the insight of people with MCI or dementia is when reflecting on their own ability to use ET, which can be investigated through comparing the self-report to an observation.

The management of everyday technology assessment (META) is a performance-based observational tool measuring an individual's ability to use ET at home or in society [24]. The subjects' management of self-chosen ETs that are perceived as relevant, well-known, and to a certain degree challenging, is observed and rated by a health professional such as an occupational therapist or psychologist. The META has been used in elderly with and without cognitive impairment [25, 26] and it reports a person reliability of 0.74 [27].

It is recommended to combine self-reports with observational assessments to get a comprehensive overview of a person's abilities [28-31]. This can be challenging in clinical settings due to organizational limitations or persons' endurance. Therefore, it seems necessary to investigate the relation between information gathered with a self-perceived report and observation. This would allow for recommendations to researchers and clinicians on how to best gain knowledge of or support a person's ability to use ET.

The present study aims to evaluate the relationship between (1) the self-perceived ability to use relevant ETs assessed by the S-ETUQ and (2) the observable performance of self-chosen and familiar, but challenging ETs evaluated by the META. To get insight into the distinctions and similarities of ET use in people with various stages of cognitive impairments, people with MCI and dementia were included. We hypothesize that the tools assessing perceived and observed abilities of ET use correlate and complement each other. Group differences between people with MCI and early dementia are expected. However, due to limited correlation studies between observations and self-perceived reports in these populations, concrete expectations cannot be formulated and this study represents an exploration in this topic. Finally, the relevance of technological items and level of challenge posed by the technologies within the self-perceived reports and observations will be described in detail. The focus of the descriptive analysis will lie on group trends to describe the composition and specific benefits of each instrument.

Methods

Study design and ethics

A cross-sectional, non-experimental design was used. The present study was approved by the Regional Ethical Committee (Registration Number 2013/5:1). Potential participants were provided with oral and written information about the study. Written informed consent was obtained from all subjects and subjects had the right to withdraw from participation at any point without giving reasons.

Participants

Participants were recruited in Sweden through memory investigation clinics, a Traffic Medicine Centre, and activity groups offered by municipalities within the Stockholm area. The inclusion criteria for all participants were: (1) age >55, (2) active users of ET, (3) compensation for visual and hearing difficulties (if applicable; e.g. glasses/hearing aids), (4) ability to conduct the interview in Swedish or English and (5) being diagnosed with mild-stage dementia or MCI. The age restriction was chosen to focus on an aging population, but also to involve individuals with early cognitive decline. The diagnosis of mild stage dementia was given by a physician according to the standardized DSM-IV criteria [32] or as major neurocognitive disorder in the mild stage according to the DSM-5 [33]. MCI was defined as (i) neither cognitively normal nor fulfilling the criteria of dementia, (ii) evidence of cognitive deterioration shown by either objectively measured decline over time and/or subjective report of decline via self-report and/or informant in conjunction with objective cognitive deficits, and (iii) preserved activities of daily living and complex instrumental functions [34]. Therefore, participants of the MCI group were included if they did not have a dementia diagnosis and fell into one of the following categories: (1) a clinical diagnose of Mild Cognitive Impairment, (2) subjective memory impairment of memory dysfunction verified by clinical tests, (3) mild cognitive dysfunction due to other diagnoses, for example Parkinson's disease, Multiple Sclerosis or stroke, and (4) cognitive impairments with a (consequential) depression as long as the depression was medically treated. Participants were excluded if they experienced temporary confusion or episodes of a (major) depression resulting in cognitive impairments. The sample size was orientated on the principles of Walter, Eliasziw [35] in combination with a power analysis with a power of 0.8 and $p<0.05$. This resulted in the aim to include at least 33 participants in each group.

Instruments

Socio-demographics and descriptive instruments

Information about the participants' gender, age, living situation, years of education, and level of participating in activities (Frenchay activity index (FAI)) [36] were gathered in an interview. The FAI captures the level of perceived activity involvement and reflects on the frequency of performing everyday activities during the past three or six months. Furthermore, cognitive abilities were measured with the Mini Mental State Examination (MMSE) [37]. Using clinical judgement and based on all available information collected in contact with the client, including the META observations and the S-ETUQ interview, the final non-standard assessment related to overall functional level and the need for assistance to live in the community was performed. This was done by the interviewer against a set of given criteria for overall functional level and independence related to the participant's requirements for living in the community using a four-graded scale; 1) independent, 2) minimal assistance or supervision, 3) moderate assistance, 4) maximum assistance. All above mentioned information were used to describe the sample.

The Everyday Technology Use Questionnaire: the Self-perceived report

The short-form version of the Everyday Technology Use Questionnaire, S-ETUQ, was used in this study. The aim of the questionnaire is to identify relevance of different ETs as well as perceptions of ability to use ET. The S-ETUQ contains 33 items representing a variety of ETs and derived via item reduction guided by assertions of a Rasch model [38]. Relevance of ET is defined in the user manual as 'technology that is available to the person, has earlier been used, is currently used, or intended to be used by the person' (p.13) [39] and only ETs relevant to the individual are included in the scoring. Table 4 illustrates the scale. The S-ETUQ requires 15-20 minutes and has been used in various populations of older adults with and without cognitive impairments, demonstrating high levels of internal scale validity, uni-dimensionality, acceptable precision in the generated measures, and evidence of validity in relation to external variables [21].

Management of Everyday Technology Assessment: the observational tool

The Management of Everyday Technology Assessment (META) is an observation-based assessment of the ability to manage ET [24]. The tool was developed to evaluate the ability to manage ET for older adults via a proxy rating in order to facilitate provision of individual support in ET management and to gain information useful for design and adaption of ETs. In total, the META consist of 17 items. In the present study, only the n=11 'Observed Performance Skills' were used (see Table 1). During the assessment, the individual is observed using ETs of their own possession and choice that are relevant, currently in use, and somewhat challenging for that person. To learn and practice the scoring, the observer/rater receive training (see section on 'data collection procedure'). Previous META studies proved acceptable person response validity and technology goodness-of-fit [27, 40]. Furthermore, the tool is sensitive to group differences between elderly without known cognitive impairment, MCI and Alzheimer's disease, and those with different severities of acquired brain injury [26].

Table 1. META observable performance skills.

Performance skill	OT's observation of the skill (at this occasion)
1. Identify and select/separate technologies 2. Identify and select services and functions within a technology 3. Perform steps and actions in logical sequence 4. Manage series of numbers/letters 5. Choose correct button or command 6. Turn a button or knob in correct direction and position 7. Use appropriate force, tempo and precision 8. Coordinate different parts of the technology 9. Coordinate the technology with another technology without physical contact between the technologies 10. Notice information and respond adequately 11. Follow verbal instructions given by automatic telephone service	*Scoring:* 4= Competent handling/management 3= minor difficulty/problems 2= major difficulty/problem 1= Deficits in this skill hinder the person's use of the technology and/or the person is in need of assistance to perform the skill competently. NA = not applicable, i.e. the skill is not needed when using the technology.

Data collection process

Data was collected between 2014 and 2016 by four experienced occupational therapists (OTs). All OTs completed a one-day ETUQ and a two-day META training course which included assessment of live- or video-taped cases prior to data collection. The training consisted of studying the manual, instructions for administration, definitions of the items, and the scoring criteria. Participants' appointments were scheduled in their own home at a mutually convenient time. The OTs collected the socio-demographic information and conducted the META and S-ETUQ on the same occasion. As the order of the tools was not expected to influence the outcome, this was not further specified. A minimum of two technological artefacts or services were assessed with the META for each participant. Additionally, the MMSE evaluations were undertaken either during the assessment occasion or the score was collected from the medical records of the participant if documented within six months.

Data preparation analysis

First, the ordinal raw score data from the assessments with the S-ETUQ and the 11 performance skill items of the META were separately transformed into abstract interval-like measures, i.e. person ability measures expressed in log-odd probability units (logits) using computer software applications of a Rasch rating scale model [38]. These analyses are able to take the different facets into account, e.g. variations in level of challenge in the items and the ETs chosen, adjusting the final personal ability measure to these facets. The S-ETUQ assesses two facets (person and ET) and thus, the software WINSTEPS [41] was applied. The META on the other hand, includes four different facets (person, rater, item, and ET) and thus a many-faceted analysis was required and the software program FACETS was used [42]. The analyses resulted in estimated measures of each person's observed (META) and perceived ability (S-ETUQ) to use ET. The use of Rasch models to develop valid and reliable measures from the META and S-ETUQ are described in detail elsewhere [21, 24]. Since the raters were not linked by assessing the same participants, they were assumed as equally severe and rater leniency was anchored at the same severity in the analysis. Raters' acceptable goodness-of-fit was set as outfit MnSq > 0.6 and <1.5 [43]. It is commonly accepted that 5% of the responses (i.e., person, technology, performance skill item and rater) are expected to be misfits by chance with z-values less than 2. In the present study, therefore, 95% of the responses were supposed to demonstrate acceptable goodness-of-fit to the Rasch measurement model and not to be a threat to validity [38].

Statistical main analysis

For the main analysis, the Statistical Package for Social Science (SPSS) was used. Demographic group differences were calculated with t-tests or Chi-square test. Since the S-ETUQ and META data showed non-normal distribution, the relationship between the personal ability measures of the S-ETUQ and META were explored with Spearman's rho coefficient (R_s) for the whole group as well as for the MCI group and dementia group. To control for significant group differences in sociodemographic information (years of education), and age as it might influence the ability to use ET, Spearman's partial correlation was additionally conducted by computing the specific syntax in SPSS. The strength of the association was determined through Cohen's guidelines for social sciences: 0.1-0.3 = small, 0.3-0.5 medium, and 0.5-1.0 = large effect [44]. To analyse the group differences regarding the S-ETUQ and META person ability measures, the Mann-Whitney test was used. Furthermore, the data was tested for outliers with the outlier labelling rule and a factor of 2.2 [45] and the Grubbs outlier test [46]. Descriptive statistics were used to give further insight into the different ETs used and performance skills reported by the S-ETUQ and META. The alpha level was set to 0.05 throughout all analysis.

Results

Participants

In total, n=38 people with dementia and n=41 people with MCI participated in the study (total sample n=79). There were no significant differences in the socio-demographics (gender, living condition and age) between the groups. The MCI group had significantly more years of education than the dementia group ($p<0.05$). The MMSE ($p<0.01$) and FAI ($p<0.01$) scores of the MCI group were significantly higher compared to the dementia group (see Table 2 for details).

Table 2. Sociodemographic characteristics, MMSE scoring, general ability measure and FAI.

	Total (n=79)	**MCI** (n=41)	**Dementia** (n=38)
Age, years			
Mean (SD)	78.6 (7.22)	77.4 (7.36)	79.8 (6.95)
Gender, n (%)			
Women	44 (55.7)	24 (58.5)	20 (52.6)
Men	35 (44.3)	17 (41.5)	18 (47.4)
Living Conditions, n (%)			
Alone	40 (51.9)	23 (57.5)	17 (45.9)
Cohabiting	37 (48.1)[1]	17 (42.5)	20 (54.1)
Education, years			
Mean (SD)	11.8 (3.52)	12.7 (.56)[2]	10.9 (.52)[2]
General Ability, n (%)			
Maximal assistance	1 (1.3)[4]	0	1 (2.6)[4]
Moderate assistance	17 (21.5)	5 (12.2)	12 (31.6)
Minimal assistance	39 (49.4)	19 (46.3)	20 (52.6)
Independent	22 (27.8)	17 (41.5)	5 (13.2)
MMSE Score			
Mean (SD)	25.2 (3.66)	26.7 (2.38)[3]	23.6 (4.11)[3]
FAI Score			
Mean (SD)	26.6 (7.54)	29.4 (6.7)[3]	23.6 (7.30)[3]

[1]*n=2 missing values (n=1 MCI, n=1 dementia)*
[2]*significant group differences (p<0.05),*
[3]*significant group differences (p<0.01),*
[4]*participant was 94 years old*

Group differences and correlations between S-ETUQ and META

Across the total sample, a small significant correlation (R_s=0.25, p=0.024) was found between META and S-ETUQ. When controlling for years of education, the correlation stayed stable (R_s=0.27, p=0.017). The correlation was non-significant when controlling for age in the total sample (R_s=.21, p=.06). The correlation between the S-ETUQ and META in the dementia group was of significant medium size (R_s=0.44, p=0.006; controlled for years of education: R_s=.42, p=.009; controlled for age: R_s=.50, p=.002), while no significant correlation was found in the MCI group (R_s=.06, p=.71; controlled for years of education: R_s=.03, p=.85; controlled for age: R_s=-.09, p=.57).

The data was examined visually and statistically tested for outliers. Two outliers were identified (see Figure 1), hence, the correlation analysis was repeated without the outliers. The result showed small variations compared to the first correlation test (Table 3) in each groups. In the total sample, the correlation was non-significant (R_s=.22, p=.052) without the outliers, however, significant when controlling for years of education (R_s=.24, p=.04).

When comparing the S-ETUQ and META scores between the groups, a significant group difference was found for the S-ETUQ scores (p<0.001), while no significant differences could be reported between groups for the META scores (p=.54).

Table 3. Means of S-ETUQ and META, correlations.

	Total (n=79)	**MCI** (n=41)	**Dementia** (n=38)
S-ETUQ person ability measure, in logits			
Mean (SD)	53.50 (5.07)	55.10 (4.35)[1]	51.70 (5.27)[1]
Range	41.20 - 70.90	47.30 - 66.40	41.20 - 70.90
META person ability measure, in logits			
Mean (SD)	1.39 (.81)	1.46 (.85)	1.32 (.78)
Range	-.37 - 4.70	.32 - 4.70	-.37 - 3.47
Correlation (with outliers)			
Spearmans' correlation of S-ETUQ and META	.25 (p =.024)	.06 (p=.71)	.44 (p=.006)
Partial Correlation controlling for education (yrs.)	.27 (p=.017)	.03 (p=.85)	.42 (p=.009)
Partial Correlation controlling for age (yrs.)	.21 (p=.06)	-.09 (p=.57)	.50 (p=.002)
Correlation (without outliers)			
Spearmans' correlation of S-ETUQ and META	.22 (p =.052)	-.01 (p=.97)	.44 (p=.007)
Partial Correlation controlling for education (yrs.)	.24 (p=.04)	-.04 (p=.81)	.42 (p=.01)
Partial Correlation controlling for age (yrs.)	.18 (p=.11)	-.15 (p=.38)	.49 (p=.002)

***Note**: A high S-ETUQ person measure indicates less difficulties using ET; a high META person ability measure indicates a high observed ability to use ET.*

[1]*significant group differences (p<0.001)*

Descriptive results of the S-ETUQ and META

The descriptive analysis of the S-ETUQ showed the relevance and self-perceived level of ability to use various technological items (Table 4).

A couple of technologies are highlighted to demonstrate the insight gained from descriptive S-ETUQ results: the TV with remote control is relevant for 100% of the people in both groups, however, one person with dementia reports not being able to use it anymore. In the MCI group, the debit card was reported as relevant by 95.1% of the group, but caused minor problems in usage for 35.9%. In the dementia group, 10.7% were not able to use the debit card anymore. 16.1% stopped using the ATM even though both technologies were perceived as relevant. Within highly relevant technologies, the individuals in the dementia group showed a tendency to need more assistance to use the ETs or stopped using them even though they were relevant. The biggest difference in relevance between the groups was described for ‘cell phone, text’, where 75.6% of people with MCI and only 21.1% of people with dementia named this technology as important. The video player, even if available and perceived as relevant, was not used anymore by 61.9% of individuals in the MCI and 83.3% in the dementia group.

With the META, n=237 performances were observed (MCI: n=121; Dementia: n=116). In the MCI group, the computer (n=29), the TV (n=25), smartphone (n=19) and mobile phone (n=17) were chosen most. In the dementia group, the most common choices were the TV (n=33), mobile phone (n=17), computer (n=9), and music player (n=9). While people with MCI had a tendency to choose information and communication technologies such as the smartphone, computer, and digital camera, people with dementia chose more often household technologies like the washing machine, power tools or coffee machine when asked to perform a challenging ET (Table 5).

Intra-rater reliability of the META

Raters demonstrated a goodness-of-fit with outfit *MnSq* between 0.97 and 1.34, which indicates an acceptable consistency (intra-rater reliability).

Table 4. Continued.

ETs	Relevance in % (of n=41 MCI/ n=38 Dementia)	Uses technology… …without another person and **without any perceived difficulties**	…without another person, but with **minor perceived difficulties**
TV with remote	100/100	75.6/76.3	14.6/5.3
Stove	100/97.4	65.9/54.1	31.7/24.3
Elevator control	100/97.4	82.9/81.1	12.2/8.1
Debit card	95.1/73.7	51.3/46.4	35.9/28.6
ATM	92.7/81.6	60.5/38.7	23.7/29
Cell phone, call	92.7/84.2	84.2/53.1	10.5/21.9
Cell phone, answer	90.2/84.2	86.5/68.8	8.1/6.3
Automated telephone service	90.2/68.4	45.9/38.5	27/15.4
Bell push bus/train	87.8/76.3	88.9/72.4	8.3/0
Radio	87.8/92.1	72.2/74.3	13.9/2.9
Automatic flush/hand drier	85.4/65.8	77.1/76	17.1/20
Bonus card	80.5/60.5	69.7/78.3	18.2/0
Cell phone, text	75.6/21.1	64.5/62.5	12.9/12.5
Coffee maker	70.7/73.7	75.9/71.4	20.7/21.4
Code lock, door	70.7/63.2	48.3/29.2	41.4/41.7
Alarm clock	63.4/73.7	73.1/50	7.7/10.7
Fire alarm	61/65.8	52/40	8/0
DVD player	56.1/29	26.1/27.3	13/0
Camera, digital	56.1/36.8	60.9/50	17.4/0
Computer, word processing	53.7/34.2	45.5/30.8	18.2/15.4
Video player	51.2/31.6	28.6/0	4.8/8.3
Internet banking	51.2/31.6	52.4/25	14.3/25
Cell phone, other	48.8/15.8	65/50	25/16.6
Remote, other	41.5/18.4	58.8/14.3	17.6/14.3
Lawn mover	36.6/39.5	46.6/66.6	20/6.6
Automatic check-in airport	36.6/18.4	20/0	20/0
Book laundry room, key	29.3/21.1	58.3/75	16.6/0
Automatic ticket machine bus/train	29.3/18.4	8.3/14.3	16.6/14.3
Computer, game	19.5/18.4	87.5/28.6	12.5/14.3
Telephone answering machine	14.6/5.3		16.6/0
Book laundry room, digital	9.8/10.5	100/100	
Burglar alarm	9.8/13.2	75/40	25/20
MP3 player	7.3/2.6	66.6/100	

Note: The percentage in 'relevance' refers to the total sample size per group. The percentage in 'level of difficulty' and 'no use' refers to the sample that indicated the technology as relevant.

	…without another person, but with **frequent/ major perceived difficulties**	… **sometimes** together with **another person**	… **always** together with **another person**	…**not** anymore or has not started using it
	2.4/0	7.3/13.2	0/2.6	0/2.6
	2.4/8.1	0/2.7	0/5.4	0/5.4
	0/2.7	2.4/2.7	2.4/5.4	
	5.1/10.7	2.6/3.6	2.6/0	2.6/10.7
	2.6/0	2.6/12.9	2.6/3.2	7.9/16.1
	0/3.1		2.6/9.4	2.6/12.5
	2.7/0		0/9.4	2.7/15.6
	2.7/0	8.1/7.7	2.7/0	13.5/38.5
			0/13.8	2.8/13.8
	2.8/5.7		0/5.7	11.1/11.4
	5.7/0		0/4	
	3/4.3	3/0	0/4.3	15.2/17.4
	9.7/12.5	0/12.5		12.9/0
	3.4/0			0/7.1
	0/4.2		3.4/8.3	26.9/16.7
	3.8/0			15.4/39.3
		12/12	4/28	24/20
	4.3/0	4.3/0	8.7/9.1	43.5/63.6
		0/14.3	4.3/7.1	17.4/28.6
	9.1/0		0/7.7	27.3/46.2
		4.8/0	0/8.3	61.9/83.3
	4.8/8.3	4.8/0	0/8.3	23.8/33.3
			5/16.6	5/16.6
		5.9/0	0/42.9	17.6/28.6
		0/6.6		33.3/20
			60/62.5	0/37.5
				25/25
			25/14.3	50/57.1
				0/57.1
				83.3/100
			0/20	0/20
				33.0/0

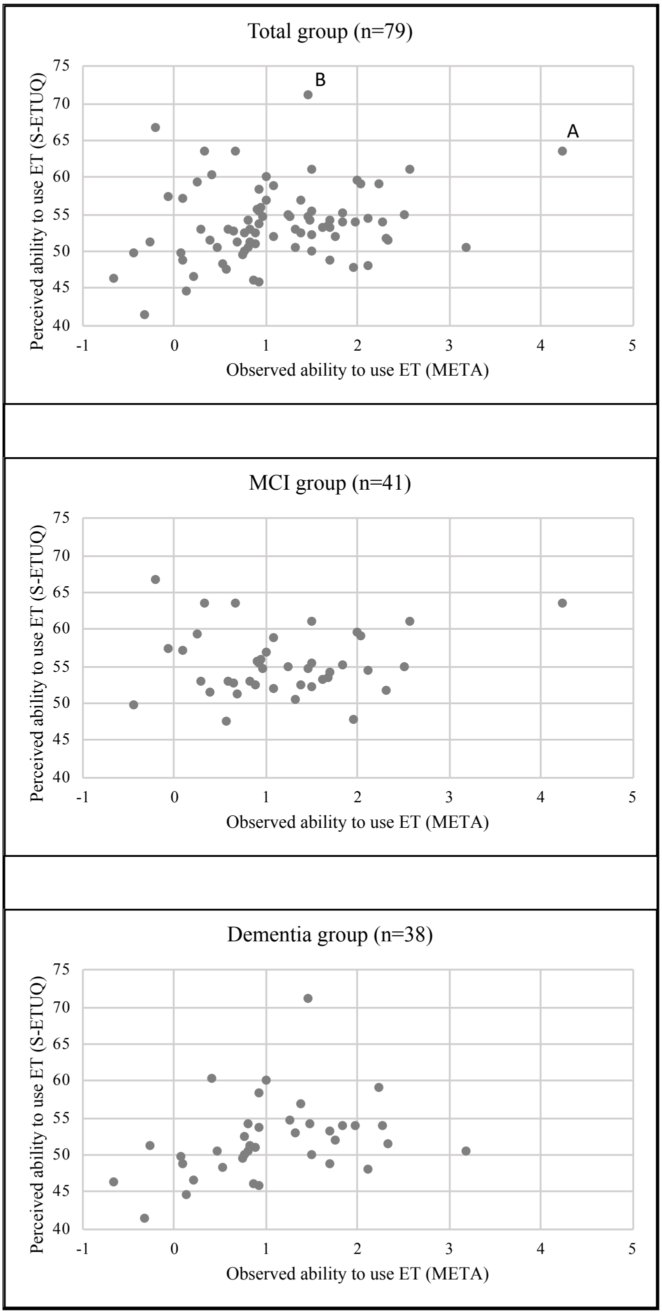


Figure 1. Scatter-Plot visualizing the relationship between measures of perceived and observed ability to use ET over the whole group, the MCI group and the dementia group. Note: higher scores indicate greater ability. Individual A: observed ability (META)=4.26 logits, perceived ability (S-ETUQ)=63.36 logits. Individual B: observed ability (META)=1.61 logits, perceived ability (S-ETUQ)=70.89 logits.

Table 5. Descriptive results META observations.

ETs	Total (n=237)	MCI (n=121)	Dementia (n=116)
TV[1]	58	25	33
Computer[1]	38	29	9
Mobile phone[1]	34	17	17
Smartphone[1]	24	19	5
Music player[1]	15	6	9
Microwave	13	7	6
Landline phone	8	3	5
Digital camera[1]	7	5	2
Transistor radio	5	1	4
Coffee maker[1]	5	1	4
Washing machine[1]	5	1	4
Alarm clock	5	2	3
Power tool	5	-	5
Stove[1]	4	2	2
Oven[1]	3	1	2
Dishwasher	2	-	2
Dryer	1	1	-
Electric kettle	1	-	1
Alarm system	1	-	1
Door code	1	1	-
Answering machine	1	-	1
Vacuum cleaner	1	-	1

[1] ETs had sub-categories to distinguish difficulty level better

Note: performed ETs were self-chosen, and perceived as challenging and relevant

Discussion

This study evaluated the relationship between the self-perceived ability to use ET and the observable performance of self-chosen and familiar, but challenging ETs in people with MCI or dementia. In the total sample, a small significant correlation was found between the self-reported perceived abilities and observed performance skills (R_s=0.25, p=0.024). When excluding two outliers, the correlation became non-significant (p=0.052). In the dementia group only, the correlation between the S-ETUQ and META showed a significant medium size (with and without outliers, and when controlling for years of education and age) suggesting a connection between information gathered with both tools. This finding might further indicate that people with mild dementia retain the ability to accurately describe their ability to use ETs and therefore, attention needs to be paid to their self-perceptions regarding technology relevance and use (see Table 4). This personal insight can inform researchers, clinicians, and relatives about problems in everyday life and potential need for support in human-technology interactions.

In the MCI group, no significant correlation was found neither with nor without the outlier, which was unexpected. Generally, the tendency of a stronger association between perceived and observed abilities to use ET in people with greater cognitive impairments was in line with previous research. In a study of people with acquired brain injury, the subsample with severe disabilities had a strong significant correlation between perceived and observed abilities to use ET, while no significant correlation could be reported in the recovery group [25]. A number of studies in aging research compared self-perceptions and other methods and found non-significant correlations [47-50]. Ready, Ott, & Grace (2004) pointed out that neither of these sources have been established to be superior and Schmitter-Edgecombe, Parsey, & Parsey (2011) concluded that tests need to be cautious in predicting functions as the they might be tapping into different aspects of the same construct [47, 48]. However, these studies did not focus on technology use and this difference needs to be kept in mind.

In the present study, the non-significant correlation in the MCI group could be explained by the self-chosen ETs being too challenging during the observation. This could result in a lower META person ability measure, which then did not correlate with the S-ETUQ perceived ability measure. Furthermore, the mean ability measures for the META were quite similar in the MCI and dementia group. This differs from an earlier META study, where the means showed to be significantly different between these groups [26]. The data collection of Malinowsky et al. (2011), however, took place about six years prior to the studied data set. Technology develops rapidly and seems to increase in complexity, which might be a possible explanation for this MCI sample to experience difficulties equal to those experienced by the dementia sample [26]. There are many different types of technologies, various brands and technological items, and in this study each participant only performed about three self-chosen ETs. A previous study ranking the level of challenge of ETs [51] identified, for example, the use of a microwave to be less complex than actions performed on a cell phone. In the present META assessment, people with dementia tended to manage less complex technologies (e.g. TV) during the observation while people with MCI managed more complex technologies (e.g. smartphone).

Therefore, the perceived ability to use ET does not always appear related to observed ability and vice versa, specifically for individuals with MCI. Perceived and observed ability should be described as two different but corresponding aspects of evaluations of ET use.

Furthermore, certain technologies seem to be slightly less relevant for people with dementia than for individuals with MCI, for example sending texts with a cell phone. When aiming to introduce new technological objects to the elderly, perceived relevance should be taken into account.

Combining the S-ETUQ and META

The S-ETUQ and META both describe the construct of technology use in older adults with cognitive impairments well. The information gathered by each instrument, however, is complementary (Figure 2). While the S-ETUQ reports on a broader range of technologies, their relevance, needed assistance, and self-perceived ability to use them, the META reveals the level of complexity the individual associates with technological item. Additionally, the META can depict the detailed performance skills during the human-technology-interaction. Health professionals could choose one or the other to investigate a specific question. However, combined, the S-ETUQ and META provide a comprehensive view of the person's ability to perform ET. This can be an advantage in the clinical setting, where the health professional might want to gain a broader understanding of the person's situation regarding their ability to use ET.

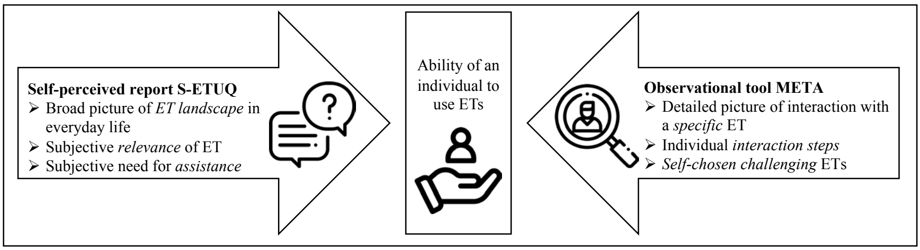


Figure 2. Unique characteristics of the S-ETUQ and META.

Disadvantages and advantages of self-perceived reports to evaluate ET use

Generally, self-perceived reports capture the conscious perceptions of an individual's perspective and require the control of higher mental processes [52] such as memory recall. In healthy individuals, a summarized self-perceived report can be memory biased [53] and furthermore describes a temporal picture of a perception with a limited amount of fluctuation. To get a more detailed picture, the experience sampling method (ESM) could be of help to describe abilities, activities, and pattern in everyday life [54]. The ESM is a data collection method where individuals repeatedly fill in short (digital) diaries reflecting on behaviour, emotion, and social context right in the moment [55]. The upcoming ‘Monitor-Mi’ study will evaluate the feasibility and validity of the ESM incorporated in a smartphone app in an MCI population (Chapter 3). The ESM has not yet been used to focus on the ability to use ET. However, it might have the potential to provide a new perspective on ET use.

Additionally, even if remembered, admitting problems in everyday life after a diagnosis of cognitive impairments can be accompanied with a feeling of shame or discomfort [56] potentially leading to a downplay of difficulties. Problems with handling everyday information or activities might be seen as an obvious sign of cognitive decline. In the specific case of the technology use described in the present study, however, it might have been easier for the individuals to admit difficulties, for example getting frustrated with using smartphone apps/ functions, as many technological devices and services are relatively new for older people. It might be seen as ‘normal’ to struggle with ET such as a smartphone – even for an older person without cognitive impairment. The complex technology can be made responsible for the inaccurate interaction rather than the person’s inability. It is not possible to differentiate this with the S-ETUQ as the self-perceived ability refers to the person-technology *interaction*. Generally, the S-ETUQ might describe an especially just picture of abilities in people with MCI and dementia and could help health professionals to get an idea of realistic problems in everyday life, as ET is intertwined in many daily activities [57].

Disadvantages and advantages of observations to evaluate ET use

In some situations, when self-perceived reports cannot be obtained such as in people with severe dementia due to limited cognitive abilities to reflect or speak [58], observations might be the only way to assess a person’s functional ability. In the present study, the participants had mild dementia and were thus able to communicate experiences. Nevertheless, the META observation was of value as a human-technology interaction with a specific self-chosen ET could be described. The person with MCI or dementia choses at least three relevant but challenging ETs themselves, giving the individual high independence of choice. The choice can inform the researcher or clinicians about level of technological complexity the person wants to take on. As pointed out before, the participants with dementia in this study seem to have an ultimately conscious tendency for easier technologies (e.g. TV or microwave), while the participants with MCI tend to choose more complex technologies such as a computer or a smartphone. During observations, this particular complexity can be a challenge for the investigator when observing ET use, as many steps are performed to produce an action (e.g. turn buttons, use appropriate force, perform steps in a certain action). When used in its intended way, the META adds information about the performance that a self-perceived report cannot provide, hence, completes the view of a person’s ET use.

Limitations

The S-ETUQ and META represent two different data-collection modes, however, both tools focus on the same construct. Therefore, the results could be influenced by the amount of overlap between the tools rather than pure differences of abilities. Technology develops rapidly and despite the fact that the S-ETUQ includes a range of items/services from various domains and the participants chose currently-available ETs during the META observation, the latest innovations might not have been evaluated in this study. Tablets, for example, seem to be becoming more interesting for older adults [59]. In the S-ETUQ and META, the participants could chose to include additional technologies perceived as relevant, but tablets were not named by this sample. Future research should pay special attention to include newly developed ETs when assessing technology use in people with MCI and dementia. The ETUQ gets regularly updated and will prospectively contribute to this question. Furthermore, during the observation, participants with dementia might have chosen technologies that were relatively easy to perform in order to not be confronted with their own impairments in that moment. It is possible that greater difficulties experienced in everyday life with ETs were not described in this study. Other limitations include the time-consuming S-ETUQ and META training, as well as the data processing procedure. This includes the Rasch analysis via additional software (WINSTEPS/FACETS), which makes the use of the instruments more complex. It is not uncommon, however, for extensive instruments to require training and supervision during examination as well as data processing. In the case of the S-ETUQ and META, online courses are currently in development, including support during the data processing. Finally, the MCI group had milder cognitive impairments and greater abilities to perform everyday activities than the dementia group. However, individuals with MCI from various origins were included and the abilities to perform complex activities in daily life may vary by MCI subtype [60]. Future studies might want take the different MCI aetiologies into account. However, in this study it was not possible due to the small sample size and the cross-sectional design. A longitudinal approach would be beneficial to get further insight, potentially also including a control group with no cognitive impairment. A control group could display the full range of abilities to perform ET in older adults with and without cognitive impairments.

Conclusions

It is important for clinicians to have valid assessment tools that can provide information on the difficulties people with cognitive impairments might have when using ET. This study emphasises the benefits of combining the S-ETUQ and META to gain knowledge about the individual's situation. While the self-perceived report describes a broad picture of the technological landscape, including perceived relevance of technological items and the need for assistance to use them correctly, the observational tool illustrates the detailed steps of a specific human-technology interaction. The latter can be used to provide information on concrete technological features that might need adjustment to improve usability. The findings indicate that people with mild dementia have an accurate insight into their own abilities to use ETs, hence, emphasising the need for clinicians and researchers to pay attention to their expressed experiences.

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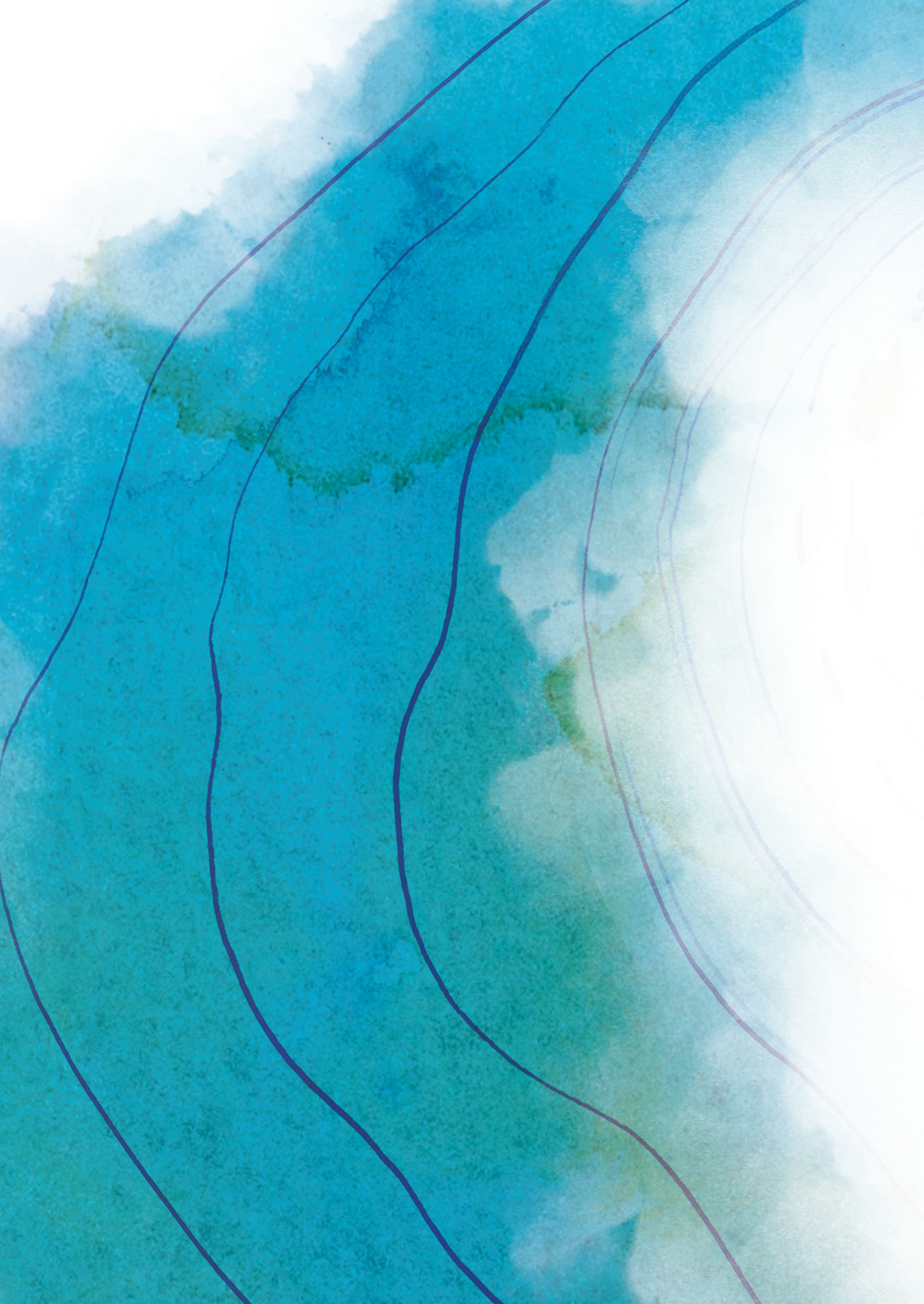

Chapter 3

Smartphone-based Experience Sampling in People with Mild Cognitive Impairment: A Feasibility and Usability Study

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(Accepted)

Abstract

Background: Daily functioning of people with cognitive disorders such as mild cognitive impairment (MCI) is usually depicted by retrospective questionnaires, which can be memory-biased and neglect fluctuations over time or contexts.

Objective: This study examines the feasibility and usability of applying the experience sampling method (ESM) in people with MCI to provide a detailed and dynamic picture on behavioural, emotional, and cognitive patterns in everyday life.

Methods: Twenty-one people with MCI used an ESM app on their smartphones for 6 consecutive days. At 8 semi-random timepoints per day, participants filled in momentary questionnaires on mood, activities, social context, and subjective cognitive complaints. Feasibility was determined through self-reports and observable human-technology interactions. Usability was demonstrated on an individual and group level.

Results: Three participants dropped out as they forgot the study instructions or to carry their smartphones. In the remaining 18 individuals, compliance rate was high with 78.7%. Participants reported that momentary questions reflected their daily experiences well. 71% of the participants experienced the increased awareness of own memory functions as pleasant or neutral.

Conclusion: Support was found for the general feasibility of smartphone-based experience sampling in people with MCI. However, many older adults with MCI are currently not in possession of smartphones and study adherence seems challenging for a minority of individuals. Momentary data can increase the insights into daily pattern and may guide the person-tailored development of self-management strategies in clinical settings.

Introduction

Clinical questionnaires are commonly of retrospective nature, therefore potentially affected by a memory-bias and thought to have low ecological validity [1]. As already cognitively healthy individuals over- or underestimate past emotions and situations [2], this method might distort reality even more when people experience cognitive deficits. Moreover, within- or between-day fluctuations of health aspects are rarely taken into account, even though emotions and well-being vary depending on daily circumstances [3, 4].

Momentary data-collection known as the experience sampling method (ESM) [5] or ecological momentary assessment [6] may offer a solution for this problem. ESM uses diaries to gather information on symptoms, mood, activities, or social interactions in the moment they occur. Repeatedly over several days, individuals fill in short questionnaires about current emotions and behaviors, which results in a high ecological validity and offers detailed insight into dynamic patterns [7]. Originally, ESM questionnaires had a paper-pencil format, but lately, mobile devices such as smartphone apps prevailed. Compared to paper-pencil diaries, technology-based ESM questionnaires can be filled in faster, thus reduce time burden, and also provide more details of the exact assessment time. Using the ESM especially in combination with personalized feedback from a health care professional increases awareness of and engagement in a healthy lifestyle and thus supports self-management [8, 9]. The term self-management can be defined as 'the individual's ability to manage their symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition' (p.178 [10]) and is a necessary skill to improve or maintain daily functioning.

A recent review reported that technology-based self-monitoring such as the ESM is already applied in various populations including people with depression, chronic pain, or other health issues to study behaviors and promote health [9]. In cognitively healthy older adults, momentary data-collection seems feasible and acceptable [11] and is promising in individuals with brain injury [12] and after stroke [13].

One group of individuals that might also benefit from this diary approach are people with mild cognitive impairment (MCI). While by definition MCI is not thought to impact daily functioning greatly [14], already small cognitive alterations can lead to changes in feelings, behaviors, self-perception, and social interactions [15]. Thus, self-management can be impaired when living with MCI.

To our knowledge, using ESM in people with mild cognitive impairment (MCI) is rare. Daily or weekly paper-pencil diaries have been used to study momentary stressors and affect in MCI samples [16, 17], but we are not aware of technology-based ESM studies in this population. Assessing the general feasibility of an unfamiliar and technology-based method is necessary, as people with MCI are commonly older and have amnestic deficits. Thus, individuals with MCI may find it challenging to process new information or handle unfamiliar technologies. Research shows, for example, that people with MCI find it more challenging to use everyday technology than older adults without cognitive impairments [18, 19], which might also impact the feasibility of smartphone-based ESM. If feasible, applying ESM in people with MCI may reveal valuable insight into daily patterns of their lives that traditional assessments have been unable to depict. Furthermore, the ESM may promote awareness and self-management in this population, thus ultimately contributing to maintained or improved well-being.

The present study aims to determine the feasibility and usability of smartphone-based experience sampling in people with MCI. An ESM app was installed on participant's smartphones and programmed with a high sampling frequency to capture various intra-individual states (i.e. mood, subjective cognitive problems) and situations (i.e. activities, social context). Self-reports of using the ESM and observations of the direct human-technology interaction were conducted as part of the feasibility assessment. Human-technology interaction refers here to the person's ability to manage the ESM smartphone app, including specific performance skills, environmental characteristics, and individual capacities.

The usability of momentary data was studied on an individual and group level focusing on subjective cognition, daily activities, and stress experienced in relation to those activities. Studying the data on a group level can provide valuable information on daily functioning of the MCI population in general, while individual data can illustrate within-person fluctuations. This may result in helpful person-tailored insights that not only foster individualized therapy but also the diagnostic process [20] and the monitoring of early changes in cognitive or behavioural alterations in MCI.

Methods

Sample

Participants were recruited from the memory clinic at the Maastricht University Medical Center (UMC) between June 2018 and January 2020. Inclusion criteria were (i) having a clinical diagnosis of MCI, according to Albert et al. (2011) [14], (ii) being in possession of a smartphone with an operational system from android or iOS, and (iii) providing written informed consent. Furthermore, (iv) a relevant other (i.e. partner, family member, close friend), selected by the person with MCI, was recruited and needed to also provide written informed consent. Exclusion criteria were: (i) insufficient abilities to participate in research (e.g. inability or lack of confidence to use a smartphone or to learn/remember the purpose of the study, as indicated by the person him-/herself and/or relevant other), and (ii) severe health problems such as a diagnosis of somatic, psychiatric, or neurological disorder causing additional cognitive dysfunction. Both exclusion criteria were based on clinical judgement from a psychologist or psychiatrist during the recruitment phase (e.g. telephone conversations with potential participant/ relevant other). The Medical Ethical Committee from the azM/Maastricht University approved the study (NL64310.068.17 / METC173055) and the protocol is registered on ToetsingOnline (64310). The authors comply with the Helsinki Declaration of 1975, as revised in 2008. All participants including people with MCI and their relevant others provided written informed consent before study participation.

Experience Sampling Smartphone App

The PsyMate smartphone app (www.psymate.eu) is a cloud-based platform developed at Maastricht University and Maastricht UMC (see Supplementary Material, Figure 1). It is a tool for repeated momentary assessments in daily life that has been extensively studied and refined in mental health care [21]. In the present study, the PsyMate was programmed to prompt participants 8 times a day over 6 consecutive days with an auditory and visual signal (‘beep’) to fill in a short momentary assessment. A high sampling frequency of 8-10 beeps per day is thought to provide insight into various daily contexts while not disrupting the ‘flow’ of everyday life. The duration of 6 days was chosen to capture week as well as weekend days. This set-up was based on previous feasibility studies [22, 23]. Beeps occurred unpredictably in semi-random time blocks of 112.5 minutes between 7.30AM and 10.30PM and were available to be filled in for 15 minutes after the beep. In total, 27 ESM items were included and could be answered on a 7-point Likert-scale or in a multiple-choice set up assessing mood (e.g. ‘I feel cheerful’), physical well-being (e.g. ‘I feel tired’), subjective cognition (e.g. ‘Since the last ‘beep’, I had memory problems’), and context (e.g. ‘Where am I?’) were included (see Supplementary Material, Table 1). Participants classified their responses individually, meaning that ‘work’, for example, could mean for one individual paid employment while another individual selected this while gardening or doing chores. A morning and evening questionnaire was also part of the ESM asking the participant to reflect on the previous night (e.g. 'I slept well') and day (e.g. 'Generally, I felt tense today') respectively. These questionnaires were not prompted via beeps, but available during the morning/evening to be filled in self-reliantly and this data was not included in this study (see Supplementary Material, Table 2). The development of this questionnaire was based on previous ESM studies [21, 24, 25]. Questions on subjective cognition were added after consulting with ESM experts and clinicians (i.e. psychologist, psychiatrist, neuropsychologist from the UMC).

Procedure

Participants were approached via the Alzheimer Center Limburg research database, consisting of patients with cognitive impairments who previously expressed their interest to be contacted for research purposes and previously recruited through UMC, or by their treating health care professional at the memory clinic. A member of the research team called potential participants, checked general eligibility, verbally explained the study, and send out information sheets. Participants were called by phone one week later and, if willing to participate, a date for the 'orientation session' was set. A standardized protocol was used: (i) orientation session, (ii) ESM training session, (iii) 6-day ESM period, and (iv) debriefing session. Only the person with MCI participated in the ESM training, ESM period, and the debriefing session, while both the person with MCI and relevant other were present at the orientation session. Sessions took place either at the hospital or at the participant's home, depending on the participant's preference. Participants could drop out at any time without providing a reason.

(i) Orientation session: After the study procedure was explained once more and final questions were clarified, informed consent was signed by the person with MCI and relevant other. Next, sociodemographic information was collected and questionnaires were filled in assessing characteristics of the person with MCI either with self- or proxy-reports. At the end of this session, a date for the ESM training session was set. The ESM training was not combined with the orientation session to not overburden participants as filling in a range of questionnaires can potentially be intense, confronting, and tiring. Thereby, we hoped to prevent participants from forgetting the ESM-training instructions due to information overload.

(ii) ESM training session: During the 30-minute training session, the PsyMate app was installed on the participant's smartphone, and the participant was instructed on how to respond to 'beeps', operate the app, and interpret the momentary questions. An example ESM questionnaire was filled in to familiarize participants with the procedure. The management of the app was observed guided by the Management of Everyday Technology Assessment (META) (see 'instruments' section) to get a detailed picture of the human-technology interaction and performance skills [26]. All participants were briefed individually. A leaflet containing all instructions and contact information was handed out.

(iii) ESM period: The PsyMate started sending 'beeps' from the moment of installation and participants could respond on this day to train filling in the momentary assessments, but were instructed that the official 6-day ESM period would start the following day. On the second ESM day, a researcher called to check-in and solve potential technical problems or provide clarification.

(iv) Debriefing session: This session took place one day after the last day of the ESM period. Participants were asked to report their general experiences using the app, received travel reimbursements, and a small gift after participation, but no financial reward.

Instruments

Sociodemographic and descriptive information

Next to sociodemographic information of the person with MCI (age, sex, education, living situation, years since first symptoms) and the relevant other (age, sex, relationship to person with MCI), reliable and valid instruments were filled in with the purpose to describe the sample. The Mini-mental state examination (MMSE) provided information on cognitive functioning[27]. If the MMSE had been administered by a healthcare professional at the memory clinic in the past 3 months, these scores were used to reduce the burden. Otherwise, the MMSE was part of the orientation session. Furthermore, the Guidelines for the Rating of Awareness Deficits (GRAD) as a semi-structured interview was included assessing the degree of awareness for own cognitive problems [28]. It compares the patient's information and relevant other's view on the patient's history. Impaired awareness is defined as the absence of knowledge recognition of cognitive deficits and its impact [28]. The Hospital and Anxiety Depression Scale (HADS) was included to generate scores for generalized anxiety and depression [29, 30], while the Perceived Stress Scale (PSS) measured the perception of stress [31]. The relevant other filled in the Neuropsychiatric Inventory Questionnaire (NPI-Q) for information on a variety of neuropsychiatric symptoms [32, 33] as well as the Amsterdam instrumental activities of daily living (Amsterdam IADL), which specially measures problems in instrumental activities in individuals with mild cognitive problems[34].

Feasibility assessment: Self-report

The feasibility was determined through the compliance rate of the ESM assessments and was regarded as satisfactory when >70% of the momentary questionnaires were filled in [12, 22]. The subjective experience of using the ESM tool was assessed during the debriefing session through a semi-structured interview, including ratings of the difficulty, time burden, interference with daily activities, and overall acceptability of the methodology. This interview followed a standardized protocol and included questions such as 'Was this a normal week' or 'Did the PsyMate app hinder your daily occupations?', which were discussed and then rated by the participant on a 7-point Likert-scale or categorically (see Table 2 for details).

Feasibility assessment: Observations

The Management of Everyday Technology Assessment (META) [35] was used during the ESM training session. This tool aims at identifying the ability to manage technology among older adults with and without cognitive impairments by observing the direct human-technology interaction. The META consists of four parts assessing (i) the observable performance skills, (ii) environmental characteristics, (iii) the person's capacity, and (iv) perceived importance of the used technology. The latter as well as general information about the technology (i.e. years of possession, amount of use) is answered by the individual via an interview, while the investigator scores the first three parts on a 4-point scale: 4= competent handling/management; i.e. no deficits in this skill disturbs or hinders the person's use of the technology (no difficulty); 3= Deficits in this skill occasionally or slightly disturb the person's use of the technology (minor difficulty/problems); 2= Deficits in this skill obviously disturb the person's use of the technology (major difficulty/problem); 1= Deficits in this skill hinder the person's use of the technology and/or the person is in need of assistance to perform the skill competently. Within part (i), 6 out of 11 performance skills were selected and scored as the other 5 were not part of using a smartphone app (e.g. coordinate different physical parts of the technology).

Statistical analyses

Descriptive analyses were conducted to summarize the socio-demographic information and background questionnaire scores. The compliance rate of the ESM day questionnaires, responses to the debriefing questionnaires, and META scores of the human-technology interaction were also analyzed using descriptive statistics. For the usability demonstration, only participants who filled in at least 30% of the ESM assessments were included as a sufficient amount of information needs to be available to describe daily patterns [36]. Thus, momentary ESM data from drop-outs collected via the PsyMate was not included in this part of the analysis. The momentary data was demonstrated on a group level using mood, context, feelings of tiredness, and subjective cognition items and analyzed with descriptive statistics to assess the usability in this population in general [12]. The variable positive affect (PA) consisted of the ESM items 'I feel cheerful', 'I feel energetic', 'I feel relaxed', 'I feel satisfied', and 'I feel enthusiastic', while negative affect (NA) included 'I feel down', 'I feel insecure', 'I feel irritated', 'I feel lonely', 'I feel anxious', and 'I feel guilty'. To demonstrate elements of daily functioning, an activity-related stress (ARS) variable was generated using 'I can do this well' (reversed), 'This requires effort from me', and 'I would rather do something else'. The ESM data collected with the PsyMate has a multilevel structure with beeps (level 1) nested within participants (level 2). Average scores of PA, NA, and ARS were thus person-mean centered to take the within-person effect into account. Cronbach's alpha for these constructs were generated through factor analyses to insure sufficient internal validity (PA=0.86; NA=0.84; ARS= 0.68). PA, NA, and ARS were average on a person mean level. Pie-charts were used to illustrate the data on a group level (Figure 2). On an exemplary level, the subjectively experienced cognitive problems of three participants were demonstrated with line-graphs over the course of the ESM period (Figure 3-5). The three participants were selected without specific criteria but with the aim to show variation, give a general impression of ESM-data, and how it can be used in clinical practice prospectively. Daily functioning using ARS was also demonstrated on an individual level by using data from three participants exemplary. STATA version 13.0 was used for statistical analyses and Excel version 16.16.19 to create graphic visualizations.

Results

Group characteristics

A total of 152 people with MCI were approached to participate in this study and n=21 people with MCI signed informed consent. The participant flow is illustrated in Figure 1. Their relevant others also agreed to participate (Relevant others: Mean age= 63.3, SD= 8.9, range 47-78 yrs.; n=6 male; n=19 partners, n=1 sibling, n=1 friend). Table 1 provides an overview of the characteristics of the total sample. In the Appendix (Table 3), details of the study completers and drop-outs can be found (see also 'Drop-outs, compliance, and self-report').

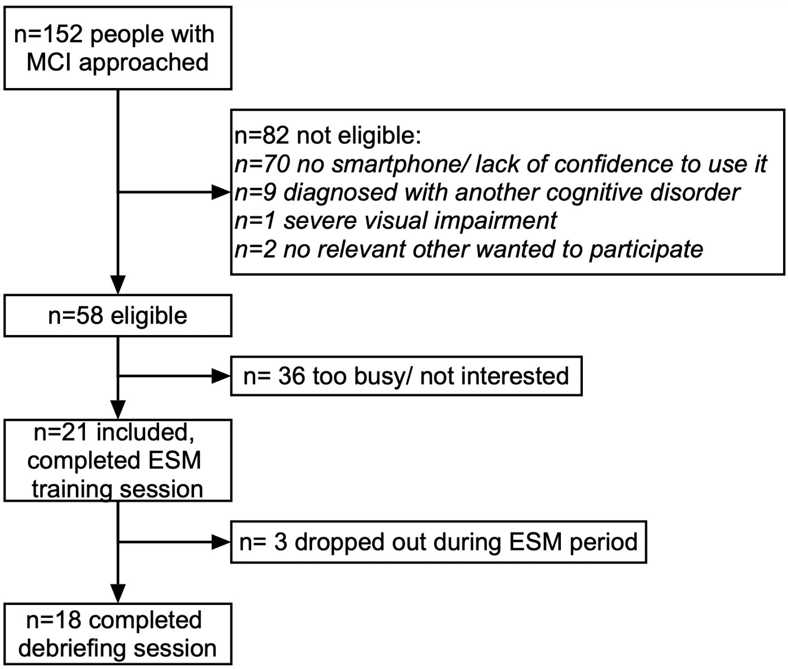

Figure 1. Flow chart of participants with MCI recruited for this study.

Table 1. Descriptive MCI group information.

Variables	Total sample (n=21)
Age in years (M, SD, range)	66 ± 7.1 (48-79)
Sex (n, % male)	16 (76.2%)
Level of education (n, %)	
Low (< 9 years)	2 (9.5%)
Middle (9-10 years)	11 (52.4%)
High (>10 years)	8 (38.1%)
Employment status (n, %)	
Retired	14 (66.6%)
Working	3 (14.3%)
Unemployed	4 (19.0%)
Living situation (n, %)	
With partner	17 (81%)
With partner and children	1 (4.8%)
Alone	3 (14.3%)
Years since first symptoms (M, SD, range)	4.8 ± 4.0 (1-19)
Cognition; MMSE (M, SD, range)	28 ± 1.26 (27-30)
Awareness; GRAD (M, SD, range)	3.4 ± 0.67 (2-4)
4: Intact (n, %)	10 (47.6%)
3: Mildly disturbed (n, %)	9 (42.9%)
2: Moderately disturbed (n, %)	2 (9.5%)
1: Absent (n, %)	-
Anxiety; HADS-A (M, SD, range)	11.8 ± 2.2 (6-15)
Depression: HADS-D (M, SD, range)	9.6 ± 1.4 (7-12)
Perceived stress; PSS (M, SD, range)	19.1 ± 4.5 (9-28)
Neuropsychiatric symptoms; NPI-Q (M, SD, range)	2.7 ± 2.1 (0-7)
Instrumental activities of daily living; IADL (M, SD, range)	57.2 ± 7.3 (45.9-69.9)

Note: MMSE score range: 0-30, with higher scores indicating less cognitive difficulties. HADS scores range: 0-21 per scale (<7 non-cases; 8-10 doubtful-cases; >11 definitive cases). PSS scores range:: 0-40, with higher scores indicating higher stress levels. NPI-Q scores range:0-36, with higher scores indicating greater amount of neuropsychiatric behavior in the past month. IADL t-scores range: 20-80, with higher scores indicating better functioning, 50=mean score at memory clinics.

3

Drop-outs, compliance, and self-report

Twenty-one individuals started the ESM period resulting in 673 beep records. Three participants had problems using the ESM and did not complete the ESM period. These drop-outs (n=3) had been eager to learn the app during the training session and their MMSE, other questionnaire scores, and general impression did not deviate outstandingly from the other participants. A statistical comparison between study completers and drop-outs was not performed due to the small sample size.

Reasons for drop-out were: Person A had problems using the right force pressing app buttons during the training session, then forgot hearing aids repeatedly (according to partner, thus not reacting to 'beeps'), did not carry smartphone along at all times, forgot appointment, and seemed to generally deny own cognitive problems. Person B expressed being very busy, only heard 'some beeps' (no hearing problems, reason unclear, technical problem unlikely according to IT specialist), and forgot appointment for debriefing session. Person C seemed generally nervous during the ESM training session (while expressing strong interest to participate), required very detailed and simple explanations of app use, and had forgotten instructions when contacted the following day. These three participants had not filled in the required 30% (16 beeps) to be included in the usability analysis, leading to a loss of 17 records (2.3%).

Eighteen participants completed the ESM period and debriefing session, resulting in 656 valid beep records. On average, participants completed 38 beeps (SD=6.8, range 23-47) of the 48 beeps. ESM compliance rate was 78.7%. Participants thought that the momentary questions reflected their experiences well (M=4.83, SD=1.62) and that the PsyMate had little influence on their mood (M=1.44, SD=1.15), activities (M=1.61, SD=1.54), social interactions (M=1.22, SD=0.73), or daily occupations (M=1.39, SD=0.85). Filling in the momentary questions made participants marginally more aware of their activities (M=2.17, SD=1.86), and moderately aware of their feelings (M=3.56, SD=2.45), and memory (M=4.56, SD=2.5). Four of the participants thought the latter was unpleasant, while 13 participants experienced it as pleasant or neutral. Table 2 provides detailed information on the general experience with the PsyMate and user-friendliness.

Observation of the human-technology interaction

The META revealed that most performance steps of using the PsyMate did not cause any difficulties (Table 3). However, *using the appropriate force, tempo, and precision* caused on average somewhat disturbances (M=3.48, SD=0.51). With regards to the environmental characteristics influencing the use of the PsyMate app during the training session, the contextual influence (i.e. presents of researchers, potentially stressful) was observed as not hindering the smartphone use (M= 3.9, SD=0.3, range 3-4), while the technological design (i.e. screen and button size) was observed as somewhat disturbing (M=3.38, SD=0.3, range 2-4). The overall judgement of the participants' capacity to use the app was reflected in *the capacity to recall necessary information* as not disturbing (M=3.86, SD=0.36 range 3-4), just like *the capacity to pay attention and focus* (M=3.81, SD=0.40, range 3-4) and *the capacity to manage stress*

(M=3.76, SD=0.45, range 3-4). Most participants (n=12) had smartphones for more than 10 years, n=5 used it for 3-9 years, n=1 for 1-2 years, and n=2 for less than a year (n=1 participant could not indicate the duration). All participants (n=21) experienced the technology as very important and not replaceable, as also reflected by n=18 using their smartphones daily and n=2 using it at least weekly (n=1 missing value).

Table 2. General PsyMate app and user-friendliness evaluation (n=18).

General PsyMate app evaluation	Scores 1 "not at all" – 7 "very much" (M, SD, range)*
Was this a normal week?	5.06 ±1.51 (2-7)
Did special events occur?	2.22 ± 1.73 (1-4)
Did the questions reflect your experiences well?	4.83 ± 1.62 (2-7)
Did the PsyMate app influence your mood?	1.44 ± 1.15 (1-5)
Did the PsyMate app influence your activities?	1.61 ± 1.54 (1-7)
Did the PsyMate app influence your social interactions?	1.22 ± 0.73 (1-4)
Did the PsyMate app hinder your daily occupations?	1.39 ± 0.85 (1-4)
Did you make mistakes when filling in the PsyMate app?	2.17 ± 0.92 (1-4)
Did filling in the PsyMate app make you more aware of …	
… your feelings?	3.56 ± 2.45 (1-7)
If so, did you experience this as pleasant/neutral/unpleasant (n)?*	7/9/1
… your memory?	4.56 ± 2.50 (1-7)
If so, did you experience this as pleasant/neutral/unpleasant (n)[1]?*	6/7/4
… your activities?	2.17 ± 1.86 (1-7)
If so, did you experience this as pleasant/neutral/unpleasant (n)[1]?*	3/14/0
Evaluation of PsyMate app user-friendliness	
Were you able to read the text on the screen well?	6.06 ± 1.70 (1-7)
Could you hear the beep well?	6.44 ± 0.86 (4-7)
Did you have problems using the PsyMate app?	1.56 ± 1.65 (1-5)
Were the verbal explanations regarding the PsyMate app clear?	6.67 ± 0.60 (5-7)
Were the written explanations regarding the PsyMate app clear?	6.67 ± 0.60 (5-7)
Were the questions from the PsyMate app unclear or difficult?	2.28 ± 1.60 (1-7)
Did you experience the use of the PsyMate app burdensome…	
… with regards to the number of beeps?	1.44 ± 0.98 (1-5)
… with regards to length of one beep?	1.44 ± 0.62 (1-3)
… with regards to the sound?	2.33 ± 2.14 (1-7)
Did technical problems hinder you from filling in the beeps?[1]	1.88 1.09 (1-4)

*Note: Drop-outs (n=3) did not participate in the debriefing session.[1]missing response (n=1). *Questions marked in this way were not answered on a 7-point Likert-scale but categorical.*

Table 3. Assessment of observable performance skills when using the PsyMate app during ESM training session.

Performance skill	Observation score (mean, SD, range)
Identify service and function[1]	3.90 ± 0.31 (3-4)
Perform actions in logical sequence	3.95 ± 0.22 (3-4)
Manage series of number/letters[2]	4.0
Choose correct button or command	3.76 ± 0.45 (3-4)
Use appropriate force, tempo, and precision	3.48 ± 0.51 (3-4)
Identify information and respond adequately	3.95 ± 0.22 (3-4)

Note: [1] n=1 missing as skill not observable. [2] n=12 missing as skill not observable.
Observational scores: range 1-4; 4 indicating competent handling/management; i.e. no deficits in this skill disturbs or hinders the person's use of the; 1indicating deficits in this skill hinder the person's use of the technology and/or the person is in need of assistance to perform the skill competently.

Usability of the experience sampling data

Daily patterns on a group level over ESM period

Participants (n=18) experienced in general a high level of PA (M=4.95, SD=.66, range 3.94-6.13), a low level of NA (M=1.95, SD=.93, range 1.07-3.92), and a low to moderate level of ARS (M=2.73, SD=.74, range 1.71-4.05). They felt moderately tired (M=3.64, SD=1.39, range 1-6.29), had low to moderate problems with their memory (M=3.01, SD=1.11, range 1.34-5.29), language (M=2.04, SD=1.15, range 1-5.21), and concentration (M=2.85, SD=1.36, range 1.05-4.96). With regard to their contextual patterns, participants spent most of their time at home (72%), engaging in household (22%) or relaxing (29%) activities, and were often in company of their partner (45%) or alone (31%) (Figure 2a-c).

To illustrate the variability that can be studied using momentary data, several descriptive examples are presented focusing on the subjectively experienced cognitive problems, daily activities, and activity-related stress in everyday life. These participants were selected without specific criteria but with the aim to visually illustrate (Figure 3-5) fluctuations within subjects, variables, and days. An unspecified heterogeneity is present, while no statistical differences within- and between-subjects were tested. Some suggestions for personalized feedback conversations between health care professionals and the individuals are provided as well.

(i) Person 1 (Figure 3) reports mainly moderate memory problems, while language and concentration abilities are overall subjectively unimpaired. 24% of the time, Person 1 engages in doing 'nothing'. This activity shows personally higher levels of ARS, while 'relaxing' has lower levels of ARS. 10% of the time, the person engages in 'work' (note: not necessary paid), which also shows personally higher level of ARS. When discussing this data, increased engagement in relaxation and coping with work could be targeted.

(ii) Person 2 (Figure 4) reports cognitive problems that fluctuate across all three domains. Conversations (2% of activity engagement) seem to be most stressful (personally higher level of ARS). Here, dealing with cognitive problems and developing coping strategies for conversations might be useful for the individual.

(iii) Person 3 (Figure 5) has subjective cognitive impairments in all three domains that fluctuate somewhat simultaneously. On some mornings, the cognitive problems seem to be 'milder'. Relaxation activities, which report low levels of ARS, are the main activity of Person 3 (48%). Nevertheless, doing nothing (12%) and working (7%) might be topics to discuss to optimize self-management.

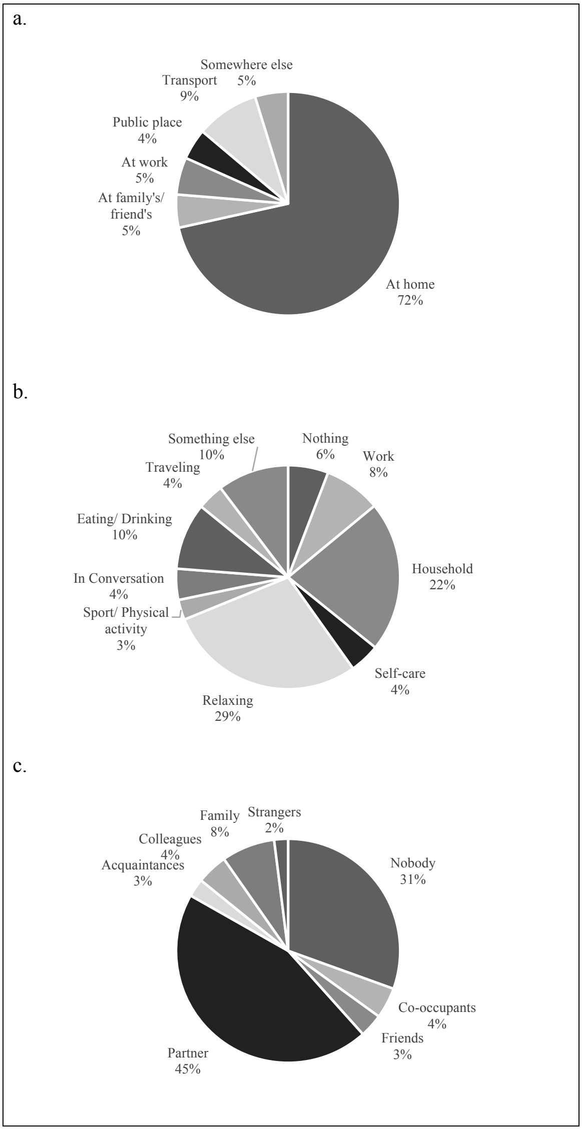

Figure 2. Group data of the reported (a) location, (b) activities, and (c) social company.
Individual profiles

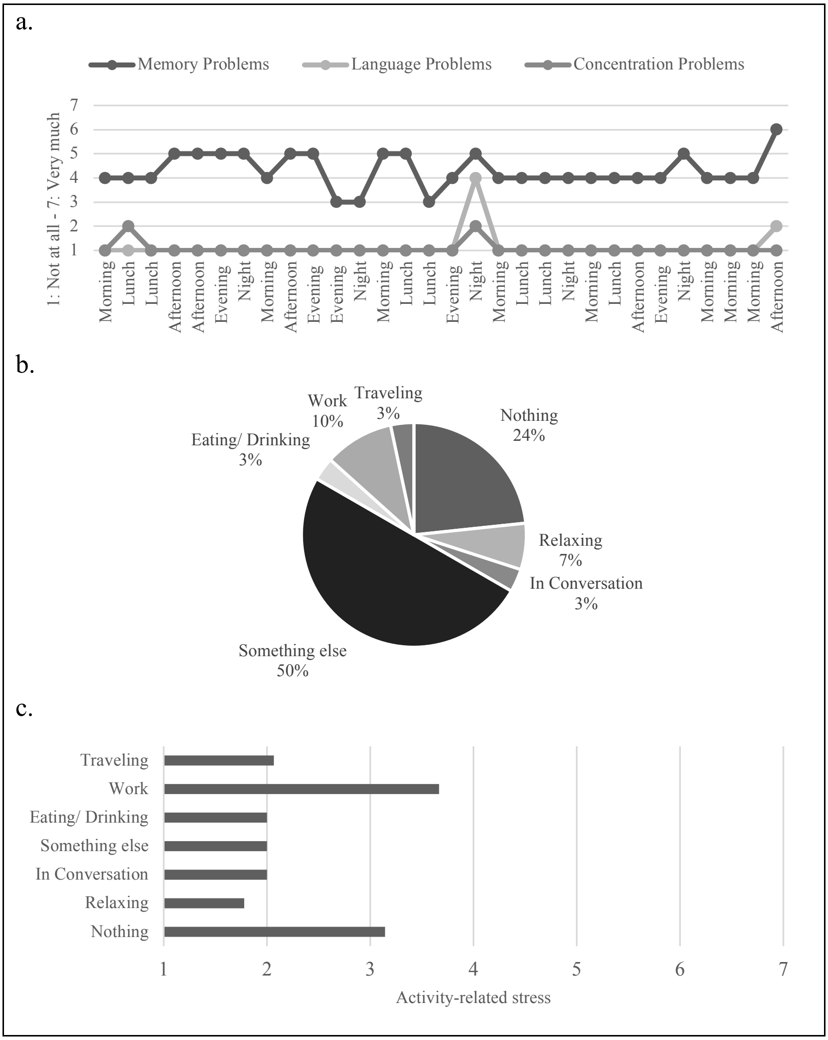

Figure 3. Person 1: (a) subjectively experienced cognitive problems, (b) daily activities, (c) level of activity-related stress related to activities.

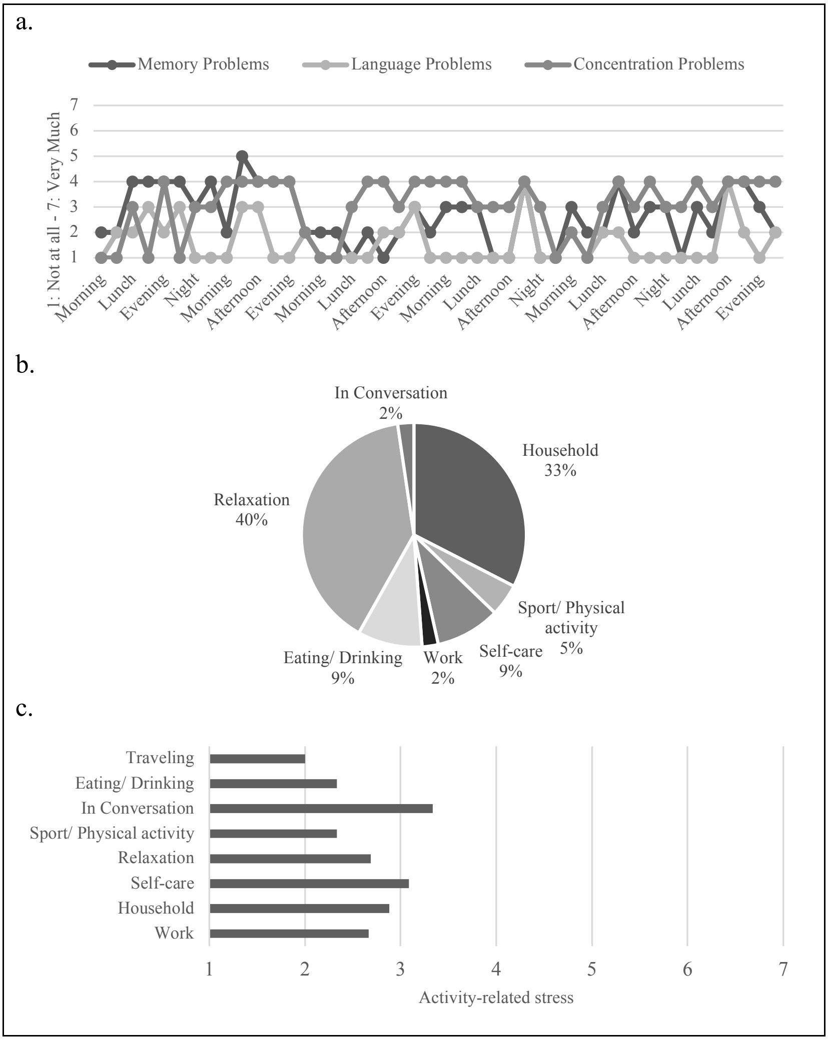

Figure 4. Person 2: (a) subjectively experienced cognitive problems, (b) daily activities, (c) level of activity-related stress related to activities.

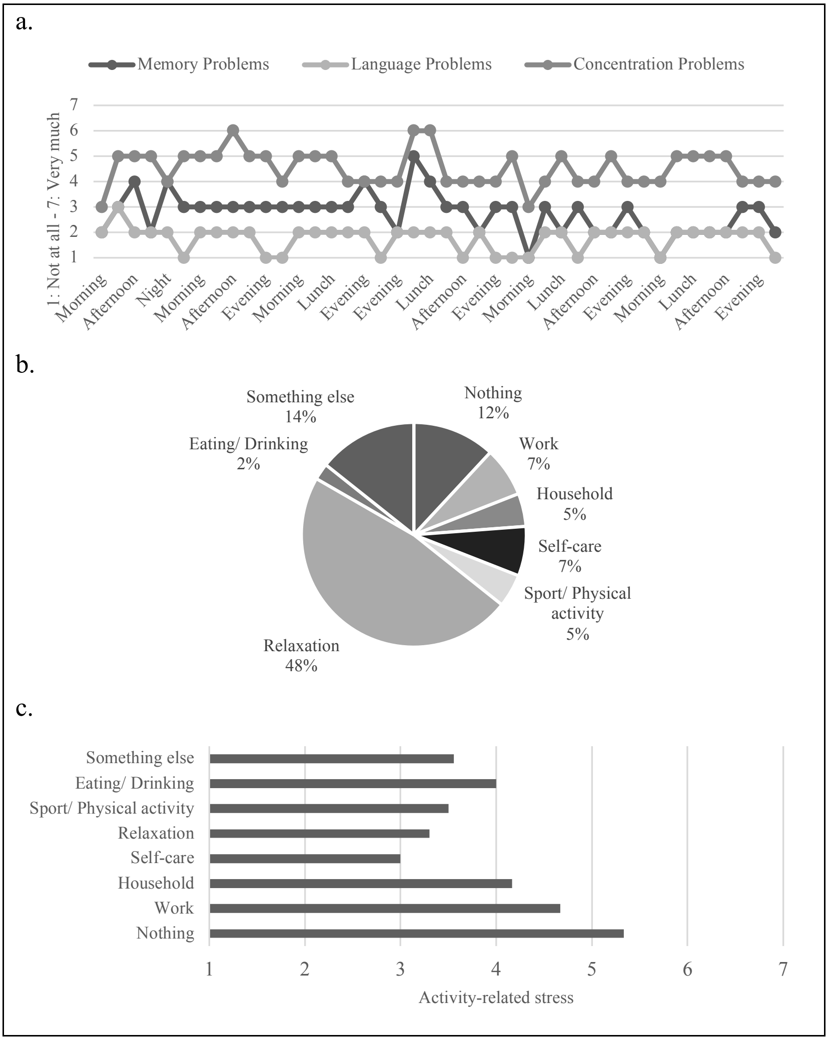

Figure 5. Person 3: (a) subjectively experienced cognitive problems, (b) daily activities, (c) level of activity-related stress related to activities.

Discussion

This study evaluated the feasibility and demonstrated the usability of smartphone-based ESM in people with MCI. Several important findings emerged: (i) in study completers, the compliance rate was high and subjective ratings of the ESM procedure were positive; (ii) the observable human-technology interaction between participants and the ESM app was generally unproblematic; (iii) raising awareness for own cognitive problems through ESM can be unpleasant for some individuals; and (iv) cognitive issues (i.e. forgetfulness) may lead to the inability to use the ESM.

Previous research found that the compliance rate, also referred to as adherence, use, or engagement, to technology-based self-monitoring such as ESM, lies between 51-86% in middle-aged and older adults [9, 37]. The reported 78.7% of completed assessments in the present study is therefore a strong indication for the feasibility of ESM in a majority (85%) of this MCI sample. A high sampling frequency, which was applied in the present study with 8 beeps per day, is not thought to hinder ESM use, while the length of the questionnaires can increase burden [38]. The overall positive participant's feedback on the procedure including the length and frequency supports the chosen ESM set-up. Additionally, the human-technology interactions was observed as overall unproblematic. Occasionally, participant's inappropriate tempo, force, or precision of clicking on app buttons disturbed usage slightly. As older adults may benefit from large buttons and screens without scroll functions [39], it would be advisable to rotate the screen, increase button sizes, or provide a touch-pen to ease the app use even further. Next to the dexterity, older adults might also have hearing issues. In the present study, one of the dropouts did not wear their hearing aids, which might have contributed to their inability to use the ESM and discontinuation of the trial.

According to the social cognition theory, self-monitoring can raise awareness for own emotions or behaviors [40]. Repeated momentary assessments can use this increased awareness to promote behavioral changes towards healthy lifestyles [21, 41] as well as improve mental well-being [42]. Within this study, there was no intention to change daily patterns, but nevertheless, participants became more aware of their memory abilities through repeated self-assessments. Thirteen individuals experienced this as pleasant or neutral, but four reported this to be unpleasant. Similar 'side-effects' of the ESM have previously been reported and a suggestions could be to use positive formulations in the ESM questions [43]. For example, instead of asking about cognitive problems (e.g. 'Since the last beep, I had memory problems), abilities could be targeted (e.g. 'I can remember well'). In the present study, the experience of using ESM was discussed during the debriefing session and in one case, a participant was advised to consult a healthcare professional for further treatment for cognition-related stress. In clinical settings, treating healthcare professionals may discuss experiences and increased awareness to develop coping strategies [44]. The individual profiles section highlight topics that may be discussed on an individual level such as activities that elicit low stress (e.g. relaxation), or the potential need for assistance or new coping strategies. Studies suggest that those feedback conversations could focus on positive emotions to increase resilience to stress [45] and stimulate goal-directed behavior [46]. This kind of feedback has shown to improve well-being, for instance, in an ESM-based intervention for carers of people with dementia [25]. The ultimate goal when using ESM is to support self-management through increase awareness for one's own abilities and orientate attention towards positive and meaningful aspects of daily life.

A small number of participants was unable to complete the experience sampling period. In older adults with undiagnosed subjective cognitive concerns, non-adherence to momentary assessments is thought to be greatly influenced by cognitive issues [47]. In the present study, predicting drop-outs using standardized instruments such as the MMSE was impossible. A systematic review reports that averaged MMSE scored in MCI samples seems to range from 23.1 to 28.7 [19] indicating a great variability of cognitive abilities in this population and that participants of this study potentially had relatively 'mild' MCI. However, the MMSE has a limited discrimination between cognitively health adults and people with MCI and other tests with a higher sensitivity (e.g. Hopkins Verbal Learning Test) could have been used to determine study eligibility [48]. All participants were eager to participate, while no clear indication for exclusion could be identified. Follow-up phone calls were helpful to notice difficulties early. Drop-outs seem to 'blame' the inability to participate on the technology (e.g. 'It did not beep'). Admitting problems with technology might be easier than admitting other cognitive deficits, as even young and healthy individuals may occasionally face difficulties with technology. Further, reduced illness-insight and cognitive deficits could have influenced the ability to use the ESM. The latter is supported by reports from participants and relevant others stating that smartphones or hearing aids were forgotten, thus interfering with the ESM use. To prevent injustice in health care, all individuals with MCI motivated to use the ESM should be given the chance to do so, but frustration can be prevented through follow-ups, close guidance, and open communication.

Generally, the ESM group data revealed subjective problems with memory, concentration, as well as language in everyday life. This finding is in line with traditional neuropsychological assessments reporting a variety of cognitive deficits in MCI, of which memory is commonly most dominant [49]. A moderate level of fatigue has also been found in an healthy sample using ESM [23] and may thus not be directly related to the cognitive deficits. To determine significant differences to healthy older adults, a control group is prospectively necessary. Furthermore, associations between daily fatigue, context, mood, and cognitive problems experienced by individuals may be studied using multilevel analysis [12].

Future directions

On an individual level, cognitive fluctuations indicate trends of diversity both within- and between subjects. The heterogeneity of the MCI group has been highlighted before [50], but this is one of the first studies to provide such a detailed insight into daily patterns using smartphone-based ESM. Next to the subjective evaluation of cognitive problems in everyday life, objective momentary cognition tasks can be added to this ESM app. The feasibility of two tasks has recently been tested in healthy individuals [51] and holds promise for future studies to describe a comprehensive picture of cognitive abilities. The ESM may also be useful to compare daily patterns of subjective or objective cognitive functioning in different neurological and psychiatric disorders.

Additionally, activity-related stress levels seem to vary between activities as working, for example, shows a trend for high levels of stress. This study is unfortunately not able to statistically explore activity patterns in people with MCI, but future research might follow-up on this idea. Research shows that complex tasks are affected early on in the process of cognitive decline [52] and cognitive difficulties may decrease the ability of individuals with MCI to work [53]. Our understanding of necessary adjustments and ways to support working, particularly employment when living with MCI are limited [54], but the here presented individual insights highlight the need to study working and employment as a potential stressor in this population further. High levels of anxiety and depression commonly observed in MCI [55] as well as in this sample, and may also stand in relation with stress and cognitive deterioration [56]. As highlighted above, developing coping strategies and focusing on positive emotions might support daily well-being including work-related stress. The ESM can be a useful tool to relate functional fluctuations with contexts and activities and thus understand patterns and networks in people with MCI both on a within- and between-subject level [57].

Limitations

Some critique regarding the ESM and study limitations need to be acknowledged. It is recommended to not overinterpret single items, but rather use momentary data as a starting point for a conversation about one's self-management and coping. Generally, many people (n=70) approached for the study had no smartphone or did not feel confident to participate in a smartphone-based study. This outcome indicates that there is a bias towards individuals with a higher technology familiarity to benefit from digital innovations in research and clinical work. Over the next decade, this bias might decrease, but researchers and clinicians need to be aware of this gap to not neglect individuals in need for support. Potentially, traditional paper-pencil diaries might be an alternative for people with MCI [16, 17] that cannot or do not want to use smartphones. However, cognitive problems (e.g. forgetting paper diary) or hearing problems (e.g. not hearing the beeps from a prompting device) could still interfere. As learning and using a new technology is an intertwined process [58] and training is a key component for older adults to increase confidence and self-efficacy when using technology [59], prospectively individuals with MCI who are not confident in their abilities to use a smartphone could receive training sessions and additional guidance. This study is unfortunately not able to determine if individuals with MCI would also be able to learn smartphone and ESM use together. Furthermore, the findings may be affected by a sex- and education-bias as 76% were male und only 10% low-educated. Additionally, the etiology of MCI was not determined resulting in a unspecified heterogeneity. As indicated by the MMSE, this MCI sample might have relatively mild cognitive problems and a replication of our findings in a broader MCI sample might be necessary to increase generalizability of the results. Detailed descriptive information about MCI sub-groups could prospectively be added. The small sample size orientated on other feasibility studies [12, 60] may limit the generalizability of the results, but the great number of assessments still results in a rich data set [21]. Finally, the study represents a specific group of people with MCI in possession of their own smartphones and this recruitment criteria needs to be kept in mind when applying the ESM in future studies or clinical settings.

Conclusion

Technology-based ESM can be a useful addition to clinical questionnaires to reveal detailed moment-to-moment fluctuations, contextual patterns, and individual differences in subjectively experienced cognitive problems, affect, and activities. This feasibility study is a relevant step to better understand and support people with MCI in their everyday lives. Momentary data may prospectively be used to study individual and group-based patterns in this population and develop person-tailored self-management strategies.

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3

Supplementary Material

Figure 1. Interface of the ESM smartphone app 'PsyMate'.

Table 1. ESM item list of the day questionnaire.

Concept/ ESM Items	Response options
Mood	
I feel cheerful.	7-point scale (1 'not at all' to 7 'very much')
I feel energetic.	7-point scale (1 'not at all' to 7 'very much')
I feel insecure.	7-point scale (1 'not at all' to 7 'very much')
I feel relaxed.	7-point scale (1 'not at all' to 7 'very much')
I feel gloomy.	7-point scale (1 'not at all' to 7 'very much')
I feel irritated.	7-point scale (1 'not at all' to 7 'very much')
I feel satisfied.	7-point scale (1 'not at all' to 7 'very much')
I feel lonely.	7-point scale (1 'not at all' to 7 'very much')
I feel enthusiastic.	7-point scale (1 'not at all' to 7 'very much')
I feel anxious.	7-point scale (1 'not at all' to 7 'very much')
I feel guilty.	7-point scale (1 'not at all' to 7 'very much')
I worry.	7-point scale (1 'not at all' to 7 'very much')
Physical well-being	
I feel good.	7-point scale (1 'not at all' to 7 'very much')
I feel tired.	7-point scale (1 'not at all' to 7 'very much')
Subjective cognitive complaints	
Since the last 'beep', I had memory problems.	7-point scale (1 'not at all' to 7 'very much')
Since the last 'beep', I had speech problems.	7-point scale (1 'not at all' to 7 'very much')
Since the last 'beep', I had concentration problems.	7-point scale (1 'not at all' to 7 'very much')
Context: Activity	
What do I do?	Multiple-choice (Work; household; self-care; relaxation; sport, physical activity; eating, drinking; traveling, on the way; in a conversation; something else; nothing)
I can do this well.	7-point scale (1 'not at all' to 7 'very much')
I would rather do something else.	7-point scale (1 'not at all' to 7 'very much')
This requires effort from me.	7-point scale (1 'not at all' to 7 'very much')
I am present with my thoughts.	7-point scale (1 'not at all' to 7 'very much')
Context: Location	
Where am I?	At home; at family's/friend's place; at work; health care setting; public space; transport; somewhere else
Context: Social Company	
With whom am I?	Partner; family; housemate; friend; colleague; acquaintance; stranger; nobody
Branching (in company/alone)	
I like this company?/ being alone?	7-point scale (1 'not at all' to 7 'very much')
I would rather be alone?/ in company?	7-point scale (1 'not at all' to 7 'very much')
General	
This alert disturbed me.	7-point scale (1 'not at all' to 7 'very much')

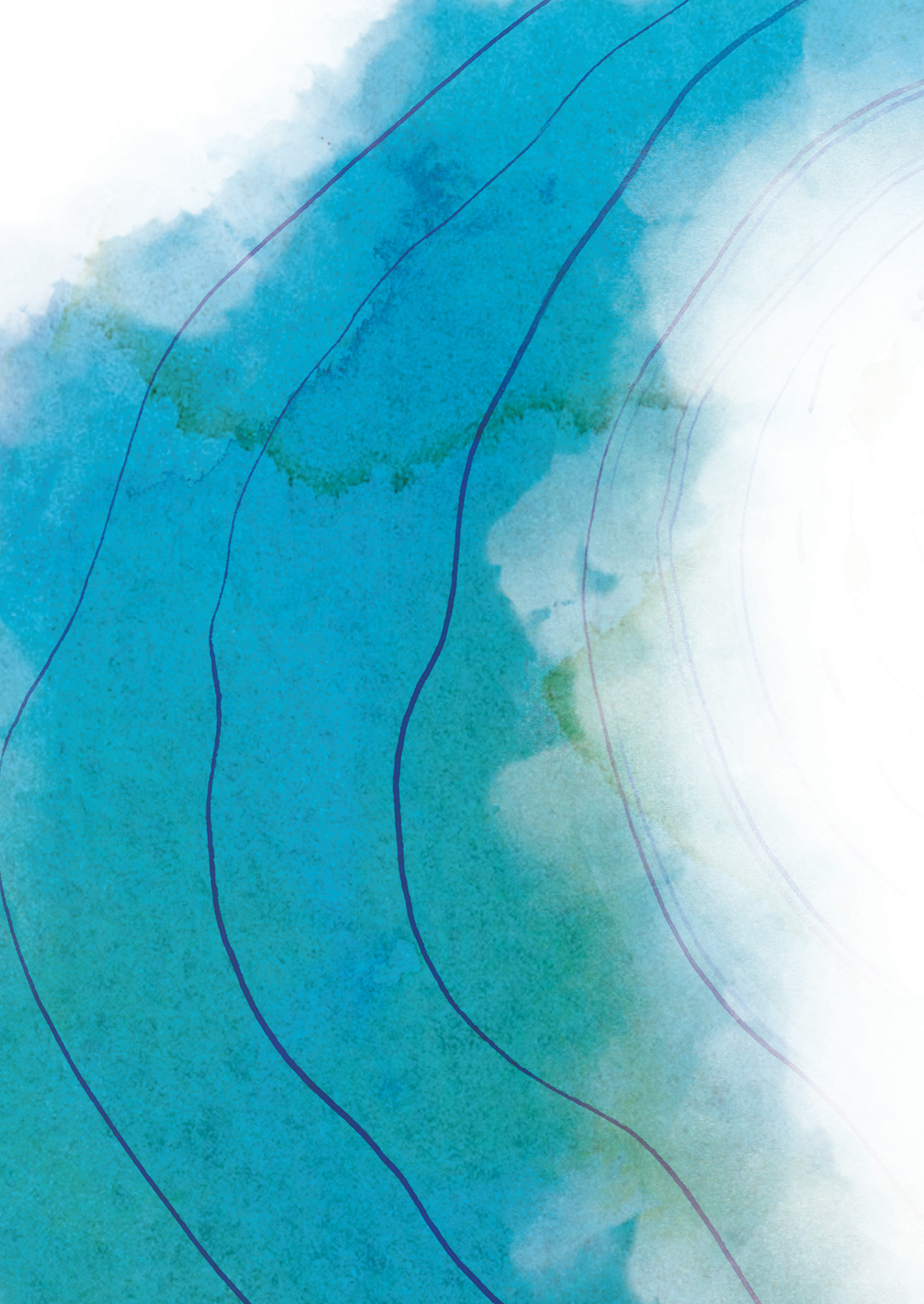
Table 2. Morning/Evening Questionnaires

Questionnaire	*Concept*/ ESM Items	Response options
Morning Questionnaire	How long did it take me to fall asleep last night?	0-5 min.; 5-15min.; 15-30 min.; 30-45min.; 45 min – 1 h; 1-2 h; 2-4 h; >4 h
	How many times did I wake up during the night?	0; 1; 2; 3; 4; >5
	How long was I awake this morning before I got up?	0-5 min.; 5-15min.; 15-30 min.; 30-45min.; 45 min – 1 h; 1-2 h; 2-4 h; >4 h
	I slept well.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	I feel well rested.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	I am looking forward to this day.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Thank you!	
Evening Questionnaire	Generally, I felt good today.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Generally, I felt tired today.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Generally, I felt tense today.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Generally, I felt like I could concentrate today.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Generally, I felt forgetful today.	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	Good night!	

Table 3. Descriptive information of the study completers and drop-outs.

Variables	Study completers (n=18)	Drop-outs (n=3)
Age in years (M, SD, range)	65 ± 6.9 (48-73)	69 ± 9.5 (60-79)
Sex (n, % male)	14 (78%)	2 (66%)
Level of education (n, %)		
Low (< 9 years)	1 (5.6%)	1 (33.3%)
Middle (9-10 years)	10 (55.56%)	1 (33.3%)
High (>10 years)	7 (38.9%)	1 (33.3%)
Employment status (n, %)		
Retired	12 (66.6%)	2 (66.6%)
Working	2 (11.1%)	1 (33.3%)
Unemployed	4 (22.2%)	-
Living situation (n, %)		
With partner	14 (77.8%)	3 (100%)
With partner and children	1 (5.6%)	-
Alone	3 (16.6%)	-
Years since first symptoms (M, SD, range)	4.3 ± 3.9 (1-19)	7.7 ± 4.0 (3-10)
Cognition; MMSE (M, SD, range)	27.9 ± 1.2 (27-30)	28.3 ± 1.5 (27-30)
Awareness; GRAD (M, SD, range)	3.4 ± 0.7 (2-4)	3.3 ± 0.6 (3-4)
4: Intact (n, %)	9	1
3: Mildly disturbed (n, %)	7	2
2: Moderately disturbed (n, %)	2	-
1: Absent (n, %)	-	-
Anxiety; HADS-A (M, SD, range)	11.6 ± 2.3 (6-15)	13 ± 1.7 (11-14)
Depression: HADS-D (M, SD, range)	9.7 ± 1.4 (7-12)	9.3 ± 1.2 (8-10)
Perceived stress; PSS (M, SD, range)	19.1 ± 4.4 (9-28)	14.7 ± 1.2 (14-16)
Neuropsychiatric symptoms; NPI-Q (M, SD, range)	2.7 ± 2.2 (0-7)	2.7 ± 2.1 (1-5)
Instrumental activities of daily living; IADL (M, SD, range)	57.0 ± 7.0 (45.9-69.9)	58.2 ± 11 (48.1-69.9)

Note: MMSE score range: 0-30, with higher scores indicating less cognitive difficulties. HADS scores range: 0-21 per scale (<7 non-cases; 8-10 doubtful-cases; >11 definitive cases). PSS scores range:: 0-40, with higher scores indicating higher stress levels. NPI-Q scores range:0-36, with higher scores indicating greater amount of neuropsychiatric behavior in the past month. IADL t-scores range: 20-80, with higher scores indicating better functioning, 50=mean score at memory clinics.



Chapter 4

Measuring Within-Day Cognitive Performance Using the Experience Sampling Method: A Pilot Study in a Healthy Population

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Abstract

Objectives: People with depression, anxiety, or psychosis often complain of confusion, problems concentrating, or difficulties cognitively appraising contextual cues. The same applies to people with neurodegenerative diseases or brain damage such as dementia or stroke. Assessments of those cognitive difficulties often occurs in cross-sectional and controlled clinical settings. Information on daily moment-to-moment cognitive fluctuations and its relation to affect and context is lacking. The development and evaluation of a digital cognition task is presented. It enables the fine-grained mapping of cognition and its relation to mood, intrapersonal factors, and context.

Methods: The momentary Digit Symbol Substitution Task is a modified digital version of the original paper-and-pencil task, with a duration of 30 seconds and implemented in an experience sampling protocol (8 semi-random assessments a day on 6 consecutive days). It was tested in the healthy population (n=40). Descriptive statistics and multilevel regression analyses were used to determine initial feasibility and assess cognitive patterns in everyday life. Cognition outcome measures were the number of trials within the 30-second sessions and the percentage of correct trials.

Results: Subjects reported the task to be easy, pleasant, and do-able. On average, participants completed 11 trials with 97% accuracy per 30-second session. Cognitive variation was related to mood, with an interaction between positive and negative affect for accuracy (% correct) (p=.001) and an association between positive affect and speed (number of trials) (p=.01). Specifically, cheerful, irritated, and anxious seem to covary with cognition. Distraction and location are relevant contextual factors. The number of trials showed a learning effect (p<.001) and was sensitive to age (p<.001).

Conclusion: Implementing a digital cognition task within an experience-sampling paradigm shows promise. Fine-tuning in further research and in clinical samples is needed. Gaining insight into cognitive functioning could help patients navigate and adjust the demands of daily life.

Introduction

Various patient populations experience confusion, difficulties to concentrate, or problems to cognitively grasp contextual cues [1-5]. To assess an individual's ability to function and cope in everyday life, neuropsychological tests are crucial. The information generated can be included in evaluating whether someone is, for example, capable of independent living or self-care [6]. Given these far-reaching consequences, it is important that the performance measured with a neuropsychological test accurately reflects performance in daily life. A review by Chaytor and Schmitter-Edgecombe (2003) suggests, however, that, when the relationship between tests and measures of daily functioning is considered, neuropsychological tests might only have moderate ecological validity for predicting everyday cognitive functioning [7].

While the general use of neuropsychological tests has gained importance in recent years, the tests themselves as well as the standardized context of administration remained largely the same [8]. Often, a battery of cognition tests (e.g., CANTAB) are used to determine someone's cognitive potential on a range of domains [9]. Individual tests often take several minutes to administer and are performed in the presence of a professional in minimum distraction environments. The goal is to determine a stable cognition factor that provides insight into the individual's general strengths and vulnerabilities [8]. However, the clinical test conditions sharply contrast with everyday environments. Everyday life is comprised of multi-sensory elements such as distracting sounds, smells, lights, or tactile stimuli. Furthermore, daily stressors and mental states can influence an individual's cognitive ability [10, 11]. Mood, for example, follows a dynamic pattern in everyday life [12] and its effect on cognition from one moment to the next is seldom considered. Moreover, cognition is known to fluctuate over the day, depending on factors such as the level of alertness or food intake [13, 14]. To improve the understanding of cognition in everyday life, the assessments need to take place in natural daily environments. Ideally, other domains such as mood and behaviours are monitored simultaneously so that underlying associations can be learned. Insight into these implicit patterns would enrich treatment for cognitive complaints and provide additional clues for recovery and rehabilitation processes, next to opportunities to tailor interventions to the individual [15]. By providing cognitive assessments within the Experience Sampling Method (ESM) this strategy becomes possible.

ESM, also called Ecological Momentary Assessments (EMA), is a (digital) structured self-assessment diary technique that allows insight into the everyday life of an individual [16]. At several (semi-) random times during the day, eHealth technologies such as Personal Digital Assistants or smartphone apps give signals (beeps) to prompt the collection of momentary experiences. At those moments, participants are asked to reflect on their current mood, environmental context, and activities and report their real-time information to the eHealth technology used. ESM is characterized by a high ecological validity as it collects experiential and contextual data in situ [17]. In-the-moment reflections reduce the recall bias that troubles retrospective self-reports [18]. Furthermore, repeated ESM measures allow a better understanding of between- and within-person variability in psychopathology and beyond [12]. As ESM can be experienced as time-consuming, the questionnaires need to be kept short and the design transparent to avoid overburdening [17].

The initial feasibility and acceptability of cognition tasks in an ESM paradigm are supported by a small number of studies, including domains such as working memory, attention, or processing speed [19]. The feasibility of a digital trail making test assessing processing speed in everyday life, for example, was found to be feasible in Chinese patients with depression [20]. Another study investigated the reliability and validity of three ambulatory cognition tasks measuring different cognitive domains (i.e., Symbol search, Dot memory, and an N-back task) [21]. Results indicated that all three tasks are feasible within an ESM paradigm and show excellent between-person reliability, reliable within-person variability, and construct validity with cross-sectional cognitive assessments [21]. In young adults, a digital processing speed task was not only feasible, but also sensitive to blood alcohol concentration [22].

Notably, most studies on daily life cognition focus only on a limited number of contextual factors in relation to cognitive performance. As everyday life is extremely complex, more research is needed to contextualize daily cognition with extensive intrapersonal (e.g., mood, age, fatigue) and contextual factors (e.g., location, company). Additionally, cognition tasks in everyday environments that take multiple minutes to perform [23] might, on one hand, provide valuable information on daily cognitive functioning. On the other hand, the length of the task can result in a relatively low sampling frequency to not overburden the participant and thus limit the exploration of cognitive fluctuations over the course of the day. In order to learn which factors influence cognitive variation over time, a higher sampling rate is required with shorter beep durations to minimize burden. This strategy would enable to study the influence of different daily situations on cognition. Ultimately, the test results could be reported back to patients and discussed together with a clinician in relation to other relevant health domains.

The present study aims to build an objective cognition task with a short duration for repeated assessments and to implement this task into a daily life setting. Accordingly, a modified digital version of the Digital Symbol Substitution Task was used within the ESM-based PsyMate™ application on an iPod for six consecutive days by healthy individuals. This digital cognition task is called momentary Digital Symbol Substitution Task (mDSST).

First, the utility and feasibility of the mDSST was determined through the participants' compliance rate and retrospective subjective experience. Second, the focus lay on validation via comprehensive contextualization of daily cognitive performance. The relationship between intrapersonal as well as contextual factors and the mDSST performance was investigated using high frequency ESM sampling (eight times a day). Prospectively, digital cognition tasks in everyday life may be relevant for improved prevention, treatment, and rehabilitation of psychopathology.

Methods

Participants

Individuals from the general population were recruited via poster advertisement at Maastricht University and through social media as seeds for snowball sampling [24]. Sample size was based on recommendations for pilot studies and other exploratory ESM studies [25-27]. In total, 45 participants provided written informed consent. All individuals were 18 years or older, had sufficient command of the Dutch language, and were able to handle an iPod with the PsyMate™ app. Exclusion criteria were medication use that influences cognitive performance (e.g., Methylfenidaat, Thyroid medication) and current treatment for mental illnesses or cognitive complaints. Ethical approval was obtained by the standing ethical committee of the Faculty of Psychology and Neuroscience, Maastricht University (ref.no.183_02_09_2017).

Measurements

PsyMate™

The PsyMate™ is a web-based platform for moment-to-moment assessment of mood and behaviour in daily life. It includes an App (iOS and Android), cloud-based data storage, and reporting tool. The PsyMate™ was developed by Maastricht University and Maastricht UMC+ (www.psymate.eu) and programmed to prompt participants using auditory signals eight times a day to complete a self-report questionnaire (approximately two minutes). Signals (beeps) were provided between 7.30 AM and 10.30 PM in semi-random time blocks of 112,5 minutes. The self-report questionnaire assessed mood, physical status (i.e., fatigue, hunger), and context (i.e., location, activity, and persons present). The mood items were combined in two independent constructs [15]: Positive Affect (PA) by averaging 'cheerful', 'energetic', 'relaxed', 'enthusiastic', and 'satisfied', and Negative Affect (NA) using 'insecure', 'down', 'irritated', 'lonely', 'anxious', and 'guilty'. The mood and physical status items were rated on a 7-point Likert scale (1=not at all, 4=moderate, 7=very) and the context items were assessed categorically. The complete item list is included as supporting information (see S1 Appendix). In addition to the self-report questionnaire on the beep level, participants were asked to complete a morning and an evening questionnaire. These additional questionnaires consisted of self-report items that assessed respectively sleep duration and sleep quality, and general appraisal of the day. Most items of the morning questionnaire were assessed categorically, whereas all the items of the evening questionnaire were rated on a 7-point Likert scale (1=not at all, 4=moderate, 7=very). Participants were included in the analyses if they completed a minimum of sixteen valid beep moments (1/3 of total), conform with ESM guidelines [28]. All participants were provided with an iPod on which the PsyMate™ app (version 2.0.0.) was installed to standardize the administration of the momentary Digit Symbol Substitution Task (mDSST). To evaluate the PsyMate™ procedure, debriefing questionnaires were provided after the ESM completion.

PsyMate™ mDSST

The mDSST is based on the Digit Symbol Substitution Task from the Wechsler Adult Intelligence Scale (WAIS)[29]{Wechsler, 2008 #27;Wechsler, 2008 #27}. It measures information processing speed and short-term working memory. The modified mDSST primarily assesses information processing speed, but not short-term working memory due to design choices (e.g., short duration, one-by-one presentation) that are part of the ESM set-up. The task was selected after consultations with psychiatric and neuropsychological healthcare professionals and scholars of daily life assessment. The constraints were that the digital cognition task could be performed multiple times per day and therefore had to be short, sensitive to cognitive fluctuations, and show no or only a small learning effect. The mDSST is thought to fulfil these criteria.

The mDSST started after the standard ESM beep questionnaire. Participants viewed an instruction screen including a button to start the task. The item screen displays the numbers 1 to 9 with a corresponding symbol at the top of the screen (encoding information). For each trial, a number was presented one-by-one in the middle of the screen. Participants had to select the corresponding symbol at the bottom of the screen (see Fig 1). Symbols were kept similar to the original Digit Symbol Substitution Task. The task duration was 30 seconds and participants were instructed to complete as many trials as possible while also being as accurate as possible. Five unique combinations of numbers and symbols with corresponding answer keys were programmed beforehand and presented in random order over the course of the 48 beeps. Outcome measures of the PsyMate™ mDSST are the number of trials (how many one-by-one trials are completed within 30-second sessions) and the percentage of correct trials (the number of correctly answered trials divided by the total number of trials).

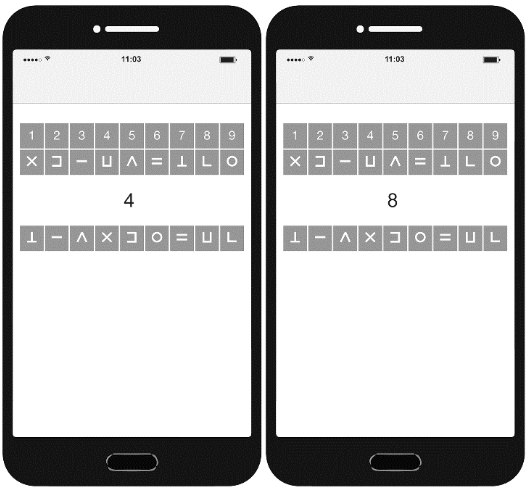

Fig 1. Momentary Digit Symbol Substitution Task in the PsyMate™ application.

Debriefing questionnaire

Participants received a debriefing questionnaire with three parts using open-ended and 7-point Likert scale questions: 1) to assess the general experience of participants throughout the week (e.g., was this a normal week, did participation influence your mood, social contact or activities); 2) to evaluate the usability of the PsyMate™ in general (e.g., was the PsyMate™ difficult to use, was the number of questionnaires burdensome, were there any technical issues); and 3) to assess the experiences with the mDSST (e.g., how well do you think you performed on the task, was the task difficult, was the task enjoyable).

Procedure

After participants provided written informed consent, a briefing session of one hour took place. Participants provided sociodemographic information including gender, age, living situation, education level, current occupation, and ethnicity. Additionally, current medication use and treatment for mental illnesses and cognitive complaints were assessed through self-reports. Furthermore, participants received an iPod (5^{th} generation) with the PsyMate™ (v2.0.0.) preinstalled. They were instructed how to use the PsyMate™ and performed a test trial to familiarize themselves with the ESM procedure. Then, the participants used the PsyMate™ for six consecutive days, starting on the day after the briefing session. On the second day of the ESM period, participants were contacted by telephone to assist with potential problems or answer questions. After the ESM period, a debriefing session of one hour took place in which participants completed the debriefing questionnaire and returned the iPod.

Statistical analyses

Descriptive statistics were used to assess participant characteristics, initial feasibility, and acceptability (frequencies) of the ESM protocol. The completion rate was calculated by comparing the mean percentage of valid beep moments to the total number of beep moments. The data collected with the PsyMate™ have a multilevel structure; beeps (level 1) were nested in participants (level 2). Average scores of the variables of interest were person-mean centred to take into account the within-person effect. In order to look at contextualized variation, dummy variables were created for location (at home versus somewhere else), company (alone versus with others), and coffee use since the last beep (yes or no). Furthermore, activity-related stress was conceptualized as an average of the items ‘I would rather be doing something else’, ‘This is difficult for me’, and ‘I can do this well’ (reverse coded). In order to look at learning effects, a log transformation of the replication (sequence number of responded beeps within subjects ranging from 1 (first beep) to 48 (last beep)) was calculated as a proxy measure of time across the six day period. Additionally, within-day time effect was explored using hour of the day and its quadratic function. To assess cognitive variation over time and to check for learning effects, multilevel regression analyses were run with the number of trials within the 30-seconds interval and the percentage of correct trials (for each assessment moment) on the mDSST as dependent variables and respectively time (i.e., log transformation of replication), hour, squared hour, and a log transformation of day number (from day 1 to day 6) as independent variables. Furthermore, multilevel analyses were run to assess the association between positive affect, negative affect, its interaction, and various other contextual factors (e.g., fatigue, distraction) as independent variables and both cognition outcomes as dependent variables. Additionally, multilevel stepwise regression procedures were used to explore the effect of individual mood items on cognition. Both forward and backward strategies were applied. The individual mood items and various other contextual factors were seen as independent variables and cognition as dependent variable. Quadratic function of age, gender, possible learning effects, and within-day effects were considered as covariates in all multilevel models. Analyses were carried out using Stata version 13.0 [30]. A two-sided significance level of .05 was used.

Results

Participants

Forty-five participants were included in the ESM protocol, resulting in 1330 valid beep records. Two participants were unable to finish the ESM protocol due to problems with the iPod device (loss of 11 records, 0.83%), one participant was excluded because the iPod was stolen (loss of 9 records, 0.68%), and two participants did not reach the criteria of at least 16 valid beeps due to various reasons (loss of 20 records, 1.50%). The complete dataset consisted of 40 participants with 1293 valid beep records. The participants' age ranged from 21 to 72 years of age with a mean of 30.4 (*SD*=14.79, *Mdn*=23.0). On average, participants completed 33 beeps (*SD*=4.9, range 21-43) of the 48 scheduled beeps. ESM completion rate was 69%. See Table 1 for descriptive statistics of the healthy population sample.

Table 1. Descriptive Statistics for the Healthy Population Sample (n=40).

	n (%)
Gender (women)	29 (72.5%)
Education level	
Secondary vocational education	5 (13%)
Bachelor degree	20 (50%)
Master degree	15 (37%)
Occupation	
Students	25 (62%)
Fulltime work	10 (25%)
Part-time work	3 (8%)
Voluntary work	1 (2,5%)
No occupation	1 (2,5%)

Feasibility

In order to assess feasibility, the available data from the debriefing questionnaire was used. One participant, whose iPod was stolen, did not complete this evaluation questionnaire, leaving 44 participants in the sample. All other analyses based on ESM/PsyMate™ data were performed with a sample size of forty participants.

Evaluation PsyMate™ procedure

Participants reported that the ESM items were a good representation of their experience (*M*=5.1, *SD*=1.26). They had no difficulty using the PsyMate™ (*M*=1.59, *SD*=1.06) and the verbal and written instructions were clear (verbal: *M*=6.64, *SD*=.53; written: *M*=6.43, *SD*=.70). Furthermore, completing the items had little influence on their mood (*M*=2.07, *SD*=1.26), activities (*M*=1.89, *SD*=1.5), and social contact (*M*=1.55, *SD*=.93). Participating in ESM did not hinder their daily activities (*M*=2.16, *SD*=1.31). With regard to the burden, participants reported that the number of beeps a day (*M*=3.23, *SD*=1.46), the duration of beep completion (*M*=2.32, *SD*=1.29), and the beep sound (*M*=3.18, *SD*=1.97) had low impact.

Evaluation of the mDSST

Participants were motivated to perform well on the mDSST (*M*=5.70, *SD*=.93), the mDSST was moderately pleasant to perform (*M*=4.43, *SD*=1.37), and participants would recommend the task to others (*M*=5.48, *SD*=1.17). Overall, the task was experienced as easy (*M*=1.80, *SD*=1.15). However, when participants had to assess their own performance retrospectively, they indicated to have performed moderately on the mDSST (*M*=4.55, *SD*=1.19). Also in retrospect, they reported to be moderately distracted during the task (*M*=3.51, *SD*=1.39).

Variation in cognition

Participants completed on average 11.39 trials within 30-second sessions (*SD*=1.32,range 3-15), with an average percentage correct of 97.11 (*SD*=2.01, range 28.6-100). The number of trials was positively associated with time (*B*=.36, *SE*=.033, *p*<.001, 95% CI=.30, .43), with a positive within-day effect for hour of the day (*B*=.03, *SE*=.007, *p*<.001, 95% CI=.01, .04), and a positive between-day effect for day number (*B*=.45, *SE*=.05, *p*<.001, 95% CI=.35, .54). The percentage of correct trials was not associated with time (*B*=-.26, *SE*=.19, *p*=.17, 95% CI=-.63, .11), with no within-day (*B*=-.04, *SE*=.04, *p*=.36, 95% CI=-.11, .04) or between-day effect (*B*=-.21, *SE*=.27, *p*=.45, 95% CI=-.74, .32).

Mood, contextual factors, and cognition

Participants experienced high positive affect (*M*=4.82, *SD*=.77, range 2.68-6.48) and low negative affect (*M*=1.65, *SD*=.47, range 1.01–2.98) throughout the study. They were a little worried (*M*=2.52, *SD*=1.00, range 1.00–4.78) and felt moderately fatigued (*M*=3.69, *SD*=1.03, range 1.55–5.77). Furthermore, they experienced low activity-related stress (*M*=2.68, *SD*=.61, range 1.37–3.73) and were moderately focused on their current activities (*M*=4.87, *SD*=.73, range 3.39–6.63). On the mDSST, they reported a low to moderate level of distraction during this task (*M*=2.88, *SD*=.88, range 1.15-4.67).

Only the main significant aggregated findings from the multilevel regression analyses are reported. Single-item analyses are included in the supplementary material (see S1 Table). Participants performed more trials (*B*=.08, *p*=.04) and made less mistakes (*B*=.62, *p*=.001) when experiencing high positive affect. They made more mistakes when experiencing high negative affect (*B*=-1.41, *p*<.001).With regard to the contextual factors, participants performed less trials when being at a different location then home (*B*=-.20, *p*=.002) and when reporting to be distracted (*B*=-.17, *p*<.001). They also made more mistakes when distracted (*B*=-.46, *p*<.001). Fatigue, activity-related stress, worrying, current company, coffee use, and being able to focus were unrelated to both cognition outcome measures. With regard to possible covariates, less trials were performed with higher age (*B*=-.001, *p*<.001), and when being male. A positive association was found between the time measures (i.e., the log-transformed replication variable as time measure, hour, squared hour) and the number of trials (e.g., the log-transformed replication variable as time measure; *B*=.36, *p*<.001). The variables with an association with the cognitive outcome measures were included in further multilevel regression models.

In the final model of the number of trials, participants again performed more trials when experiencing high positive affect (*B*=.20, *p*=.01).. In addition, a positive learning effect was present with more trials completed over time (*B*=.38, *p*<.001).. Moreover, participants completed less trials when distracted (*B*=-.19, *p*<.001) and at an older age (*B*=-.0008, *p*<.001). The results of this analysis indicated that the six predictors explained 36% of the overall variance (16% within-subject variance and 47% between-subject variance).

In the final model of the percentage of correct trials, a positive interaction effect was found between positive affect and negative affect for the percentage of correct trials. In other words, the influence of negative affect on correctness is limited when positive affect is high, but stronger when positive affect is low (*B*=.71, *p*=.001). Additionally, participants made more mistakes when distracted (*B*=-.46, *p*<.001). The results of this analysis indicated that the four predictors explained 3% of the overall variance (5% within-subject variance and 0.1% between-subject variance). The results of the final models are presented in Table 2 (the number of trials) and Table 3 (the percentage of correct trials).

Table 2. Multilevel Regression Analyses of Mood, Distraction, Time, and Age during the mDSST on the Number of Trials.

	Number of trials				
	B	**SE**	**p**	**95% CI**	
Model 1			<.001*		
Positive Affect	.20	.08	.01*	.04,	.36
Negative Affect	.27	.17	.12	-.07,	.60
Interaction between Positive Affect and Negative Affect	-.04	.04	.34	-.12,	.04
Distracted	-.19	.02	<.001*	-.22,	-.15
Time$^{\$}$	.38	.03	<.001*	.31,	.44
Age^2	-.0008	.0001	<.001*	-.001,	-.0005

*Note. CI = Confidence Interval, Time$^{\$}$ = log-transformed replication score, Age^2 = squared age. *p < .05.*

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Table 3. Multilevel Regression Analyses of Mood and Distraction during the mDSST on the Percentage of Correct Trials .

	Percentage of correct trials				
	B	SE	p	95% CI	
Model 1			<.001*		
Positive Affect	-.89	.43	.04*	-1.73,	-.05
Negative Affect	-4.10	.97	<.001*	-5.99,	-2.21
Interaction between Positive Affect and Negative Affect	.71	.22	.001*	.28,	1.15
Distracted	-.46	.11	<.001*	-.67,	-.26

*Note. CI = Confidence Interval. *p < .05.*

Exploratory analyses on individual mood items

The pairwise correlation of individual mood items ranged from .42 to .74 for positive affect items and from .30 to .54 for negative affect items. These correlations disregard the nested within-subject variance. When subtracting by subject means to assess within-subject variance only, the correlations were considerably lower (from .24 to .63 for positive affect, and from .18 to .40 for negative affect). Results are presented in the supporting information (see S2 Table).

Exploratory multilevel regression analyses of individual mood items on cognition were computed, using mood items as independent variables and cognitive outcome measures as dependent variables (see S3 Table for an overview). Only the items cheerful and energetic were positively associated with the number of trials (respectively B=.12, p<.001; B=.06, p=.02). The positive affect items cheerful (B=.54, p<.001), relaxed (B=.51, p<.001), and satisfied (B=.53, p=.001) were positively associated with the percentage of correct trials. All negative affect items were negatively associated with percentage of correct trials.

In order to weigh item covariation, both forward and backward stepwise strategies were applied. These results are also presented in the supporting information (see S3 Table). In the backward-approach, cheerful remained the most prominent positive mood variable associated with the number of trials (B=.13 p<.001) and the percentage of correct trials (B=.36 p=.03). For the negative affect items, irritated showed a positive association with the number of trials (B=.07 p=.01), whereas anxious was negatively associated with the percentage of correct trials (B=-.69 p=.01).

Discussion

A novel digital cognition task, the mDSST, was evaluated for use within a daily life ESM protocol. The first aim was to assess the utility and initial feasibility of the mDSST. The second aim was to study the preliminary internal validation of measuring cognition in daily life, both as varying over time and in relation to contextual and intrapersonal factors.

Feasibility and utility of the PsyMate™ mDSST

ESM data from three participants were removed due to circumstances outside our control and two participants did not reach the minimum beep requirements, leaving 40 participants with analysable data. Participants completed on average 33 beeps within a 48-beep protocol, resulting in a completion rate of 69%. The participants' overall experience was positive; ESM completion did not hinder daily life and the burden was reported as acceptable. This result is satisfactory and similar to other ESM research with and without a cognition task [19, 23, 31, 32]{Band, 2017 #13;Moore, 2017 #18}. The cognition task was evaluated as easy and pleasant to perform. Task motivation was high and participants felt competitive towards the task, although several participants indicated that this competitiveness faded towards the end of the six day assessment period. This is an indication that the task is less suited for longer data collection periods, as is relevant in clinical practice. Solutions in this context should alternate the task with another cognition measure or provide cognitive assessments in a subset of beep-moments each day.

Contextualization of the PsyMate™ mDSST

Information processing speed was measured with a modified momentary version of the Digit Symbol Substitution Task that yielded two outcome measures: the number of trials within 30 seconds and the percentage of correct trials [29]. On average, participants completed 11 trials within 30-second sessions (speed) and answered 97% correct (accuracy). This high correctness score indicates that the task is easy, something that is also reflected in the participants' retrospective evaluation. The choice for a DSST-based task was deliberate because it proved sensitive to detect cognitive complaints and changes in cognitive functioning in clinical samples [33, 34]. As this is a cognitive healthy sample, it is unsurprising that participants made little mistakes. Generally, cognitive performance can be viewed as a trade-off between accuracy and speed. Here, accuracy showed a ceiling effect (with reduced variability) while speed is a more sensitive measure. Only the number of trials showed a learning effect over time, with a slight increase of trials during the first half of the ESM period followed by a stabilization. Additionally, more trials were completed towards the end of the day.

The relationship between mood and the accuracy outcome reflected a positive interaction effect between positive affect, negative affect, and the percentage of correct trials. In situations were negative affect is high, participants also tend to make more mistakes, an effect that is strongest when positive affect is low. Zooming in on individual mood items, only cheerful and anxious seemed to be associated with the accuracy outcome. Therefore, it has merit to unpack the positive and negative mood aggregations to get relevant information and clues for clinical practice. A possible explanation could be that people are less able to focus on a task when they feel anxious. This negative influence of mood on cognitive performance is observed in clinically depressed patients and might be caused by distractions due to ruminations [35, 36]. Here, participants who got distracted during the task also made more mistakes. As distraction was assessed after task completion, it is possible that participants who noticed that they made mistakes, consequently scored higher on distraction. Overall, the explained variance for accuracy in relation to mood and contextual factors is neglectable (3%) and combined with a ceiling effect it seems to be an irrelevant chance finding in a population without cognitive complaints.

A small positive association was found between mood (positive affect and more specifically cheerful) and the speed outcome. Participants who were more cheerful also completed more trials irrespective of learning effects. With regard to contextual and intrapersonal factors, a small negative association was found between age and speed, indicating that older participants overall completed less trials. The original Digit Symbol Substitution task is known to be sensitive in identifying age-related performance and processing speed often explains a large part of the variance in these studies [37]. Our modified digital version of the task was also age-sensitive. With regard to gender, males seemed to perform slower compared to females, an effect that disappeared in the final model. In the original Digit Substitution tests, men also seem to perform less well when averaged [38, 39]. In this convenience sample however, females were overrepresented (73%) and further research is needed.

Similar to the accuracy outcome, higher distraction was associated with fewer completed trials within a 30-second session. Here, the overall explained variance is clearly higher (36%). There is more variation over time with only a small learning effect. Indicating that the speed outcome is more suited to assess cognition in the current sample.

Several daily life factors were explored. Only distraction was associated with cognition, whereas other factors such as activity-related stress, company, and being able to focus were not. One other study looked at situational cues in relation to cognitive performance within an ESM paradigm. They found that working memory performance did not differ for people at work versus at home, but that short-term memory improved during worktime [40]. Possibly, processing speed is less sensitive to contextual changes.

Notably, fatigue did not vary significantly over time and had no effect on cognition. This was surprising, since other studies with a young population show a negative impact of tiredness on mental processing and increased difficulties with focusing on a task [41-43]. However, the mDSST was only 30 seconds while a standard cognitive assessment is longer (often 2 minutes). It is likely that the association of cognition with fatigue only occurs in longer or more demanding tasks, which are not suited to the ESM paradigm.

Strengths and limitations

The PsyMate™ app with the mDSST can be used on an individual's own smartphone and is not restricted to the provided iPod. The use of cognition tasks on smartphones is feasible [44, 45]. By using iPod devices across participants, the device specifications during the initial validity were standardized. In the early stages of task development, uncertainty about test characteristics, design choices, and device specifications exists. The use of the same device, the iPod, reduced the uncertainties about factors that might influence outcome across the study sample. In later stages, the influence of different devices (i.e., own smartphones) will become less problematic as the goal shifts towards an evaluation of within-person variability for clinical purposes.

Additionally, the mDSST was developed in an inter-professional context. Researchers (both in mental health and somatic care), physicians, neuropsychologists, clinicians, and software developers worked together to accomplish a tool that can prospectively be used across disciplines and in daily practice.

Although the study has several advantages, limitations need to be kept in mind. First, our sample was mainly restricted to female students (70% women, 61% students, median age was 23). The study, however, was intended as a pilot study using convenience sampling to assess initial feasibility and validity. The mDSST has shown merit for daily life assessment and age sensitivity of the mDSST could already be indicated. Nonetheless, using a more heterogeneous population, a broader age range (through stratification), as well as populations with cognitive impairments, will increase knowledge about task sensitivity as well as a more diverse examination of between- and within-person variance in task performance.

Second, technical problems have influenced the study outcomes. The beep questionnaire was only available for ten minutes. When participants initiated the questionnaire within the ten-minute boundary, the software should allow them to finish the task. However, the PsyMate™ app stopped after 10 minutes sharp, which resulted in 15 unfinished and interrupted tasks. The number of trials statistic was unreliable in these cases. Furthermore, the first participants indicated not hearing the beep sound (leading to eighteen missed beeps). This problem was resolved by a system update that enabled a louder and more intrusive beep sound. The technological issues concerning the mDSST seem unlikely to have influenced the performance outcome; the proportion of correct answers was high. Nevertheless, participants experienced those issues as unpleasant and in the future a more reliable technology should be used.

Finally, while reflecting on the task, two participants reported making mistakes by accidentally pressing the wrong symbol since the buttons were too small. In addition, sixteen participants reported that they made mistakes due to the slow processing of the iPod. The mDSST could be improved by using smartphones with a larger screen so that the size of the buttons is increased. Another option would be to rotate the screen into landscape mode.

Future direction

In light of the current study results, several questions still remain. Valuable, but limited information on the psychometric properties of the 30-second mDDST is gathered. It would be interesting to examine if the time interval can be further decreased (e.g., to 15 seconds) and still yields reliable data. A shorter duration could increase the feasibility and decrease the influence of distractions. The outcome measures of the task can be extended to include response time (milliseconds) to get an idea about the influence of distractions on task performance. Future research should investigate construct validity by comparing performance to the paper-and-pencil version of the DSST. This study is in progress. Sleep quality was assessed using the morning questionnaire, but not taken into account here due to power problems. Poor sleep quality can negatively influence cognitive performance during the day [13]. More attention needs to be paid to the influence of sleep quality and fatigue on cognitive performance in daily life. Smartwatches exist that can accurately track sleep patterns. It would be interesting to link objectively gathered sleep data to ESM cognition and fatigue outcomes.

The mDSST predominantly focuses on processing speed, but other tasks measuring additional cognitive constructs could be designed for use in an experience-sampling paradigm. This would allow to compute the discriminant validity, as was done by Sliwinski and colleagues [21]. However, it is unclear whether a battery of mobile cognition tasks is necessary for clinical purposes. Insight into daily cognitive fluctuations may be possible with an a specific cognition task. Repeated cognitive testing using ESM technology do not allow for a conclusive assessment across cognitive constructs, cross-sectional test batteries are more suited for this purpose. Gaining a general sense of cognitive functioning in relation to other domains can provide concrete ideas on how to deal with cognitive deficits that are individually relevant during everyday life. Although in this study, the various contextual factors did not show an effect on cognitive performance it still seems valuable to examine possible links more closely. All these factors arguably influence daily cognitive functioning and should further be explored in the context of the rehabilitation process.

Clinical implications

This study is moving away from a classic cross-sectional assessment of cognition to an ecological assessment of cognitive variation. The combination of the mDSST with experience sampling allows for an examination of the link between cognition and contextual and intrapersonal information. ESM is used in clinical assessments and to implement in situ interventions in various populations. Using this method helps to raise awareness for variability patterns in everyday life and it is used to support self-management and improve well-being [15]. Thus, making ESM a valuable tool to supplement assessments of behaviour and mood, with the monitoring of cognitive abilities and its daily fluctuations.

Cognitive impairments are known to influence recovery and self-care behaviour in various populations. In schizophrenia and depression, there is evidence that cognitive deficits contribute to poor psychosocial functioning [46, 47], while in bipolar disorders there is an association between cognitive dysfunction and the course and length of the illness [48]. A study by Cameron et al. (2010) showed that in patients with heart failure, cognitive problems hindered decision-making [49]. Individuals with diabetes, who experienced greater cognitive difficulties, were less likely to remain adherent to exercise or diet [50]. Teaching individuals self-management techniques is generally recommended for rehabilitation purposes, for example after a stroke [51].

Understanding oneself and one's (cognitive) abilities is important for self-management. By monitoring cognition with ESM and by examining the results afterwards, knowledge can be gained about previously non-transparent patterns between behaviour, mood, and cognition, facilitating this understanding [15]. Learning when difficulties arise and under which circumstances, could help patients to adjust their tasks accordingly. Individuals might thus plan their days according to their cognitive abilities and, for example, schedule resting moments when cognitive exhaustion occurs. Keeping track of minor changes towards recovery motivates patients and helps clinicians to adapt treatment plans. Cognition tasks like the mDSST can be helpful in supporting future treatment, prevention, and rehabilitation.

Conclusions

Adding a digital cognition task to an experience-sampling paradigm proved to be feasible in healthy individuals. The mDSST is promising and sensitive to detect cognitive variability in relation to mood, intrapersonal, and contextual factors. Although the task seems promising, further exploration is needed in more diverse age samples and in clinical populations with cognitive complaints. The implementation could be improved by providing some minor changes to the task (e.g., larger buttons or screen for visibility). It is clinically relevant to grasp how cognition fluctuates over time and relates to daily life functioning. By providing patients and clinicians with feedback on this data, cognitive rehabilitation and self-management can be improved.

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Supporting information

S1 Appendix. Experience sampling items.

Experience Sampling Protocol: Beep Questionnaire.

	Item	7-point Likert scale or categorical options
1	I feel cheerful	1 = not at all 4 = moderate 7 = very much
2	I feel energetic	1 = not at all 4 = moderate 7 = very much
3	I feel insecure	1 = not at all 4 = moderate 7 = very much
4	I feel relaxed	1 = not at all 4 = moderate 7 = very much
5	I feel down	1 = not at all 4 = moderate 7 = very much
6	I feel irritated	1 = not at all 4 = moderate 7 = very much
7	I feel satisfied	1 = not at all 4 = moderate 7 = very much
8	I feel lonely	1 = not at all 4 = moderate 7 = very much
9	I feel enthusiastic	1 = not at all 4 = moderate 7 = very much
10	I feel anxious	1 = not at all 4 = moderate 7 = very much
11	I feel guilty	1 = not at all 4 = moderate 7 = very much
12	I'm worrying about things	1 = not at all 4 = moderate 7 = very much
13	I generally feel well at the moment	1 = not at all 4 = moderate 7 = very much
14	What am I doing	work, school/housekeeping/self-care/relaxing/sport/eating, drinking /traveling, on the road/having a conversation/something else/nothing
15	I can do this well	1 = not at all 4 = moderate 7 = very much
16	This is difficult for me	1 = not at all 4 = moderate 7 = very much
17	I would rather be doing something else	1 = not at all 4 = moderate 7 = very much
18	I am focused	1 = not at all 4 = moderate 7 = very much
19	Where am I	at home/at someone else's home/work, school/public space/on the road/somewhere else
20	Who am I with	partner/family/housemates/friends/colleagues/acquaintances/strangers, others / nobody
21a	Company: I like this company	1 = not at all 4 = moderate 7 = very much
22a	Company: I would rather be alone	1 = not at all 4 = moderate 7 = very much
21b	Alone: I like being alone	1 = not at all 4 = moderate 7 = very much
22b	Alone: I would rather be in company	1 = not at all 4 = moderate 7 = very much
23	I don't feel well	1 = not at all 4 = moderate 7 = very much
24	I am tired	1 = not at all 4 = moderate 7 = very much
25	Since the last beep I have used	alcohol/medication/coffee, caffeine/smoking, nicotine/cannabis/other drugs/nothing
26	mDSST instruction screen	
	mDSST	30 seconds task duration
27	I got distracted during the task	1 = not at all 4 = moderate 7 = very much
28	This beep disturbed me	1 = not at all 4 = moderate 7 = very much
29	Thanks!	

S1 Table. Individual multilevel regression analyses.

Table. Multilevel Regression Analyses of the Explored ESM Items Separate for Number of Trials and Percentage of Trials Correct.

	Number of trials					Percentage of trials correct				
	B	**SE**	**p**	**95% CI**		**B**	**SE**	**p**	**95% CI**	
PA	.08	.04	.04*	.005,	.16	.62	.19	.001***	.24,	.99
• Cheerful	.12	.03	<.001***	.06,	.18	.54	.15	<.001***	.24,	.85
• Energetic	.06	.03	.02*	.01,	.12	.14	.14	.32	-.14,	.42
• Relaxed	.01	.03	.78	-.05,	.06	.51	.14	<.001***	.23,	.80
• Satisfied	.02	.03	.51	-.04,	.08	.53	.16	.001**	.22,	.83
• Enthusiastic	.02	.03	.53	-.04,	.07	.13	.14	.34	-.14,	.39
NA	-.03	.06	.58	-.14,	.08	-1.41	.28	.000***	-1.96,	-.86
• Down	-.04	.03	.24	-.10,	.03	-.40	.17	.02*	-.74,	-.06
• Insecure	-.01	.03	.80	-.08,	.06	-.62	.18	<.001***	-.96,	-.27
• Irritated	-.004	.03	.89	-.06,	.05	-.54	.14	<.001***	-.81,	-.27
• Lonely	.02	.04	.68	-.06,	.09	-.56	.19	.003**	-.94,	-.19
• Anxious	-.005	.05	.92	-.10,	.09	-.90	.25	<.001***	-1.39,	-.41
• Guilty	-.03	.04	.41	-.12,	.05	-.65	.21	.002**	-1.07,	-.23
Fatigue	-.01	.02	.52	-.06,	.03	-.06	.11	.59	- .29,	.16
Worrying	.02	.03	.54	-.04,	.07	-.26	.14	.07	-.54,	.02
Focused	.01	.03	.70	-.04,	.06	.10	.13	.44	-.16,	.36
Distracted	-.17	.02	<.001***	-.21,	-.13	-.46	.11	<.001***	-.67,	-.25
Act. stress	.02	.03	.44	-.03,	.07	-.11	.14	.44	-.38,	.17
Location	-.20	.06	.002**	-.32,	.07	.26	.34	.45	-.41,	.93
Company	-.13	.07	.05	-.26,	.001	-.02	.35	.95	-.72,	.67
Coffee use	-.08	.09	.37	-.25,	.09	-.37	.46	.42	-1.28,	.53
Age²	-.001	.0001	<.001***	-.001,	-.0005	-.0002	.0003	.50	-.0007,	.0004
Gender	-1.09	.44	.01*	-1.95,	-.22	.04	.72	.96	-1.38,	1.46
Time	.36	.03	<.001***	.30,	.43	-.26	.19	.17	-.63,	.11
Hour	.03	.01	<.001***	.01,	.04	-.03	.04	.36	-.11,	.04
Hour²	.001	.0002	.001**	.0003,	.001	-.001	.001	.30	-.004,	.001

Note. CI = Confidence Interval, PA = Positive Affect, NA = Negative Affect, Act. Stress = Activity-related Stress. Location = dummy variable of being at home versus somewhere else. Company = dummy variable of being alone versus with others. Coffee use = dummy variable of coffee use since the last beep versus no coffee use. Age^2 = quadratic function of age. Time = log-transformed replication score. Hour = hours within a day. Hour^2 = quadratic function of hour. *$p < .05$. **$p < .01$. ***$p < .001$.

S2 Table. Correlations between mood items.

Table A. Pearson Correlates for Single Positive Affect Items.

Variables	1	2	3	4	5
Overall variance					
1. Cheerful	-				
2. Energetic	.74***	-			
3. Relaxed	.47***	.42***	-		
4. Satisfied	.59***	.55***	.57***	-	
5. Enthusiastic	.67***	.66***	.48***	.62***	-
Within-subject variance					
1. Cheerful	-				
2. Energetic	.63***	-			
3. Relaxed	.29***	.24***	-		
4. Satisfied	.43***	.39***	.41***	-	
5. Enthusiastic	.50***	.50***	.30***	.43***	-

Note. All p < .001.

Table B. Pearson Correlates for Single Negative Affect Items.

Variables	1	2	3	4	5	6
Overall variance						
1. Down	-					
2. Insecure	.45***	-				
3. Irritated	.44***	.27***	-			
4. Lonely	.49***	.40***	.30***	-		
5. Anxious	.45***	.54***	.32***	.46***	-	
6. Guilty	.33***	.34***	.31***	.30***	.48***	-
Within-subject variance						
1. Down	-					
2. Insecure	.33***	-				
3. Irritated	.40***	.18***	-			
4. Lonely	.35***	.25***	.20***	-		
5. Anxious	.31***	.37***	.22***	.28***	-	
6. Guilty	.27***	.20***	.21***	.18***	.29***	-

Note. All p < .001.

S3 Table. Multilevel stepwise regression analyses.

Table A. Multilevel Stepwise Forward and Backward Regression Analyses of Individual ESM Items for Number of Trials.

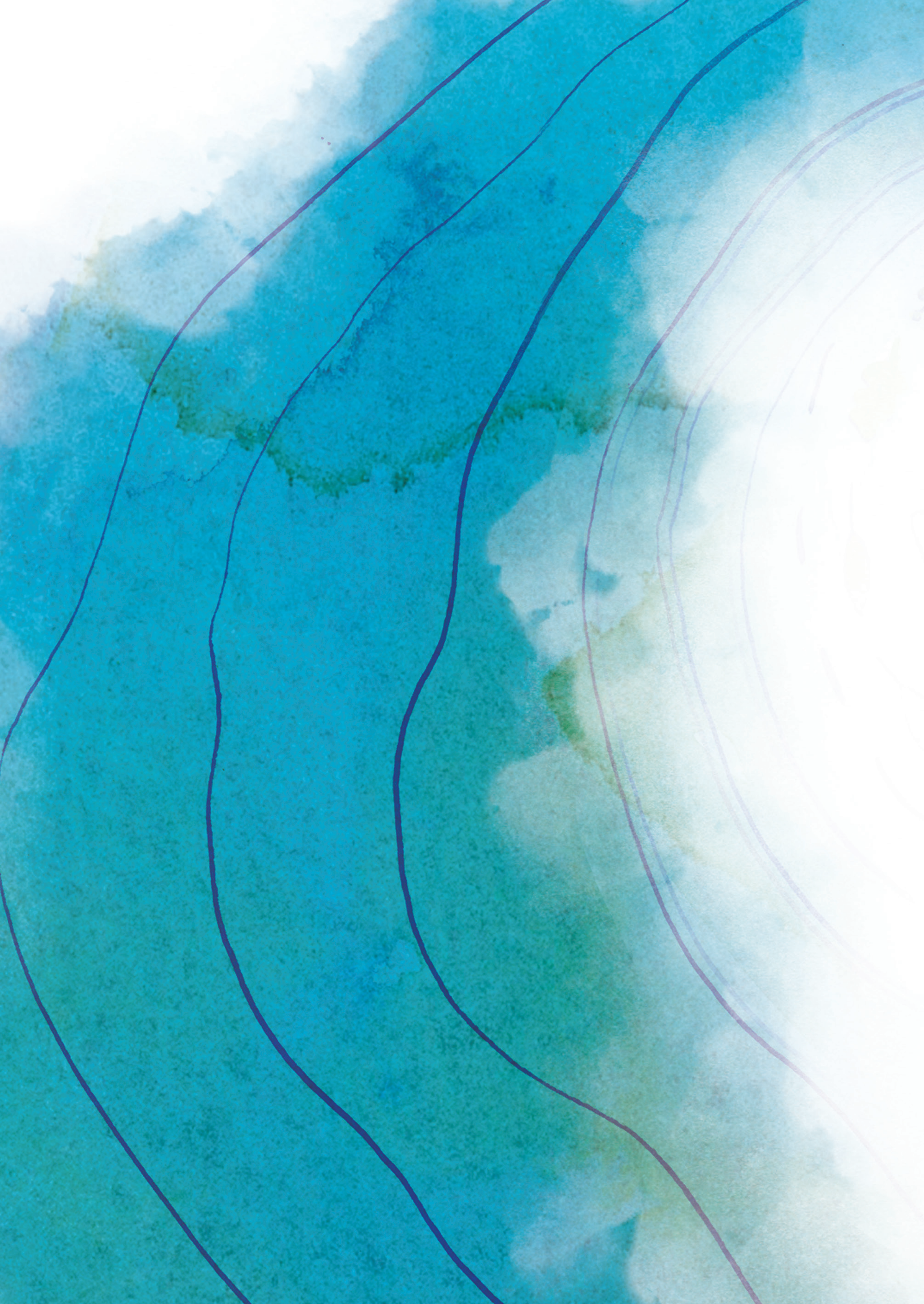
	Number of trials				
	B	**SE**	**p**	**95% CI**	
Forward (overall)			< . 001***		
• Cheerful	.10	.03	< . 001***	.05,	.16
• Location	-.003	.06	.96	-.13,	.12
• Distraction	-.19	.02	< . 001***	-.23,	-.15
• Time	.35	.03	< . 001***	.28,	.41
• Hour	.13	.05	.01	.03,	.23
• $Hour^2$	-.004	.002	.02	-.007	-.0006
• Age^2	-.0008	.0001	< . 001***	-.001	-.0006
Backward (overall)			< . 001***		
• Cheerful	.13	.03	< .001***	.07,	.19
• Irritated	.07	.03	.01*	.02,	.12
• Age^2	-.0008	.0001	< .001***	-.001,	-.0006
• Time	.35	.03	< .001***	.29,	.42
• Hour	.12	.05	.02*	.02,	.22
• $Hour^2$	-.004	.002	.03*	-.009,	-.0004

Note. CI = Confidence Interval. **p* < .05. ***p* < .01. ****p* < .001.

Table B. Multilevel Stepwise Forward and Backward Regression Analyses of Individual ESM Items for Percentage of Trials Correct.

	Percentage of trials correct				
	B	**SE**	**p**	**95% CI**	
Forward (overall)			< . 001***		
• Cheerful	.33	.17	.06	-.007,	.66
• Relaxed	.21	.16	.20	-.11,	.52
• Insecure	-.36	.18	.05	-.72,	.002
• Irritated	-.27	.15	.07	-.57,	.02
• Distracted	-.43	.11	< .001***	-.63,	-.22
Backward (overall)			< . 001***		
• Cheerful	.36	.17	.03*	.04,	.69
• Relaxed	.31	.16	.05	.003,	.62
• Anxious	-.69	.26	.01*	-1.19,	-.19
• Location	.75	.35	.04*	.05,	1.44
• Distracted	-.53	.11	< .001***	-.74,	-.32

Note. CI = Confidence Interval. **p* < .05. ***p* < .01. ****p* < .001.



Chapter 5

Digital Assessment of Working Memory and Processing Speed in Everyday Life: Feasibility, Validation, and Lessons-Learned

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Internet Interventions (2019)

Abstract

Objectives: Cognitive functioning is often impaired in mental and neurological conditions and might fluctuate throughout the day. An existing experience-sampling tool was upgraded to assess individual's cognition in everyday life. The objectives were to test the feasibility and validity of two momentary cognition tasks.

Methods: The momentary Visuospatial Working Memory Task (mVSWMT) and momentary Digit Symbol Substitution Task (mDSST) were add-ons to an experience sampling method (ESM) smartphone app. Healthy adults (n=49) between 19 and 73 years of age performed the tasks within an ESM questionnaire 8 times a day, over 6 consecutive days. Feasibility was determined through completion rate and participant experience. Validity was assessed through contextualization of cognitive performance within intrapersonal and situational factors in everyday life.

Results: Participants experienced the tasks as pleasant, felt motivated, and the completion rate was high (71%). Social context, age, and distraction influenced cognitive performance in everyday life. The mVSWMT was too difficult as only 37% of recalls were correct and thus requires adjustments (i.e. fixed time between encoding and recall; more trials per moment). The mDSST speed outcome seems the most sensitive outcome measure to capture between- and within-person variance.

Conclusions: Short momentary cognition tasks for repeated assessment are feasible and hold promise, but more research is needed to improve validity and applicability in different samples. Recommendations for teams engaging in the field include matching task design with traditional neuropsychological tests and involving a multidisciplinary team as well as users. Special attention for individual needs can improve motivation and prevent frustration. Finally, tests should be attractive and competitive to stimulate engagement, but still reflect actual cognitive functioning.

Introduction

Cognition is a key determinant when it comes to the question how well an individual manages daily tasks and performs everyday activities. Only if a person can remember, concentrate, communicate, plan, and reason, is he/she able to cope with the requirements of life. The link between cognition and functioning has been demonstrated not only in people with cognitive impairments [1] or mental health issues [2], but also healthy individuals [3]. Therefore, it is necessary to take cognition into account when aiming to understand daily patterns or support functioning.

Memory functions, processing speed, and other cognitive abilities are usually assessed in clinical or laboratory settings rather than natural environments. Brief cognitive screenings are used in routine primary care to identify individuals at risk for cognitive dysfunction, while comprehensive, multidimensional neuropsychological batteries have the purpose to establish a diagnose or functional profile [4]. Casaletto & Heaton (2017) highlight the 'common complaint' regarding neuropsychological assessments to be 'their apparent lack of relevance to the real-life problems' (p.11) [5] that individuals experience in their everyday life. Furthermore, as doctor visits occur periodically [6], the assessments provide a rather temporary picture of one's cognitive ability. This traditional approach may thus affect the ecological validity of neuropsychological test results [7].

An empirically validated daily diary method, known as the Experience Sampling Method (ESM) or Ecological Momentary Assessment (EMA), allows to collect real-world information [8-10]. Digital ESM technologies using smartphone apps prompt participants repeatedly over the day to reflect on their own behaviour, affect, and contextual factors [11, 12]. Over the last decade, interest has increased to not only depict affect and activities with experience sampling, but also to include the area of cognitive functioning. It is relevant to bridge the lab-life gap and observe cognition closely in everyday life and in a more dynamic way [13]. Learning that cognitive performance can fluctuate over time and grasping which daily circumstances influence cognitive performance can help patients to optimize activities in daily life. Momentary cognition tasks provide a more dynamic understanding of cognition throughout the day that can be clinically relevant when recovering from somatic or psychological complaints. For ecologically valid cognitive assessments, digital diary methods delivered via smartphone apps offer unique opportunities.

The status of cognitive assessments in everyday life

Cognitive assessments in everyday life through technology are relatively new. A recent review by Moore, Swendsen, and Depp (2017) has identified 12 studies that use self-administered digital cognitive assessments [14]. A brief literature search on PubMed identified 13 additional studies (see Figure 1 for a visualized summary).

Various cognitive domains are considered for the assessments in everyday life. Often, more than one task is used and multiple domains are evaluated. Working memory and attention/reaction time are most prevalent, which may be explained by the fact that these domains are generally relevant for various patient populations as they are affected in neurological conditions [15, 16] as well as mental illnesses [17, 18]. Participants' age ranged from adolescents to older adults. While some studies focused on healthy individuals, others included patient populations. Normative data remains unavailable and, therefore, the validation of mobile cognitive assessments in healthy individuals is still relevant.

To describe the internal validity of the momentary tasks, the contextualization of the momentary performance is a key element. Therefore, previous studies took intrapersonal factors such as age, mood, and drug use into account. Furthermore, psychometric properties of the mobile cognition tasks, including between-person reliability, within-person reliability, and construct validity should be elaborated [14].

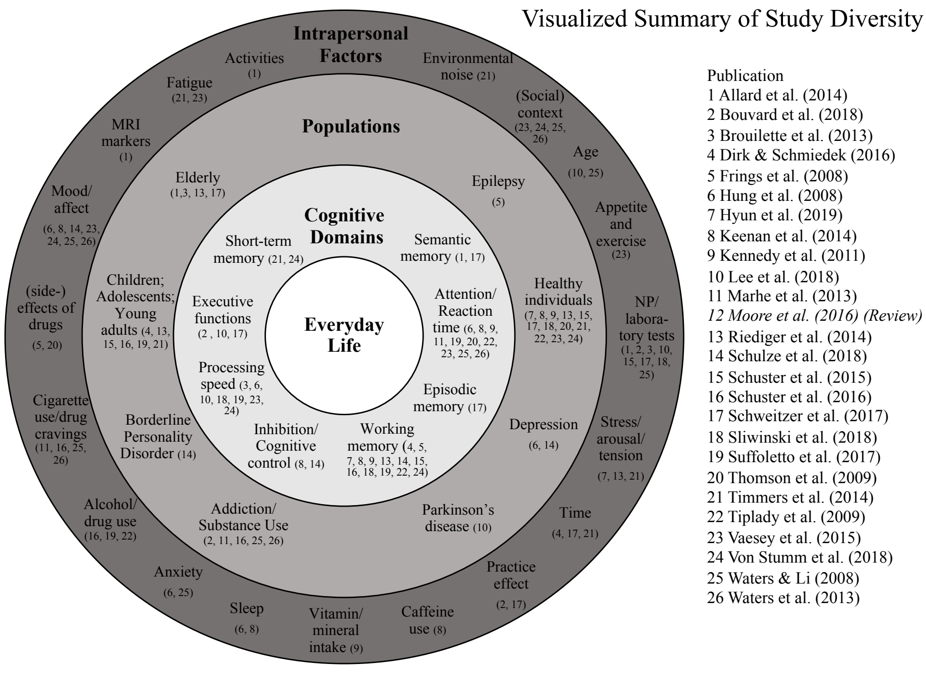


Figure 1. Visualized summary of studies focussing on cognitive assessments in everyday life by cognitive domains, populations, and the intrapersonal factors set in relation with outcome(s) (see Publication); this summary does not aim to be exhaustive, but provides a first overview of the field). NP = Neuropsychological. [19-25].

The present study

The present study aims to evaluate the feasibility and validity through contextualization of two newly developed, short momentary cognition tasks implemented in an existing platform with a high sampling frequency. A high sampling frequency of eight times a day allows to describe a detailed picture of daily mood and cognition fluctuations. Furthermore, high-frequency sampling is the standard in this particular ESM platform [9], which is broadly used in research as well as in clinical settings [26, 27]. This ESM tool has the advantage of being available for both Android and iOS users. It is crucial to build on existing technologies rather than reinventing new devices to support sustainable use. Therefore, this ESM tool is an important target for future cognition task development. A healthy sample was recruited to perform a visuospatial working memory task and a processing speed task within a momentary assessment. Additionally, the ESM items assess a wide range of momentary intrapersonal and situational factors such as mood and social context.

To determine the feasibility, completion rate and participant satisfaction were used. Validity was assessed through an exploration of the contextual variation of cognitive performance. Cognitive performance measured with the momentary cognition tasks was evaluated by relating cognition outcomes to each other as well as to relevant ESM-measures such as mood, fatigue, and current company. The results are discussed with regard to lessons-learned during the development process and future implications. Prospectively, researchers and clinicians who are already familiar with the smartphone app can include cognitive measures in everyday life alongside affect and context to understand and support various patient populations.

Methods

Participants

Recruitment from the general population was performed via snowball sampling, using media advertisements and the personal network as seeds. Sample size was based on previous feasibility studies using the same experience sampling app and aimed for a minimum of 30 participants [28, 29]. Fifty-one participants provided written informed consent. Participants were at least 18 years old, had a full understanding of the Dutch language, and were able to handle a smartphone device (Android) with a beta version of the PsyMate™ app (version 213–253) (see section 2.2.1 for details). Participants who could not use their own smartphone device were provided with a 5th generation iPod on which the same version of the PsyMate™ app was installed. Individuals were excluded based on medication use that could influence cognitive performance and current treatment for cognitive or mental health complaints. The standing ethical committee of the Faculty of Psychology and Neuroscience, Maastricht University (ref.no.183_02_09_2017) granted ethical approval and the study was carried out in accordance with the Declaration of Helsinki.

Measurements

No traditional neuropsychological tasks were included in this study as the focus lay on the contextualization of the momentary cognition scores and their within-day fluctuation. To validate ESM items, the correlation between similar and dissimilar ESM items is suggested [9]. As suggested by Chen, Cordier & Brown (2015), patterns of associations between items of quality of experiences (i.e., cognition) and other momentary items such as emotions related to the experiences should be logical, thereby supporting the internal validity of the data [30].

Experience Sampling Method (ESM)

The ESM was administered using the PsyMate™ Suite; a smartphone app and a cloud-based platform developed by Maastricht University and Maastricht UMC+ (www.psymate.eu). PsyMate™ is a parametrized and flexible tool for repeated assessments in everyday life. The application was programmed to emit an auditory and visual prompt (beep signal) eight times a day for six consecutive days, signaling the availability of a self-report questionnaire. These beep questionnaires were provided at semi-random time blocks of 112.5 minutes, between 7.30 AM and 10.30 PM and remained available for response during 15 minutes. Beep questionnaires included mood (i.e., positive and negative affect), physical status (i.e., hunger, fatigue, and pain), and context (i.e., location, activity, and social company) items as well as the two cognition tasks. Positive affect (PA) included the items 'cheerful', 'energetic', 'relaxed', 'enthusiastic', and 'satisfied', while negative affect (NA) was composed of the items 'insecure', 'down', 'irritated', 'lonely', 'anxious', and 'guilty'. In line with ESM guidelines[9], a minimum of 16 valid beep questionnaires (1/3 of total) per participant had to be completed to be included in the analyses. One ESM assessment including the two momentary cognition tasks would not take longer than 2 minutes to complete.

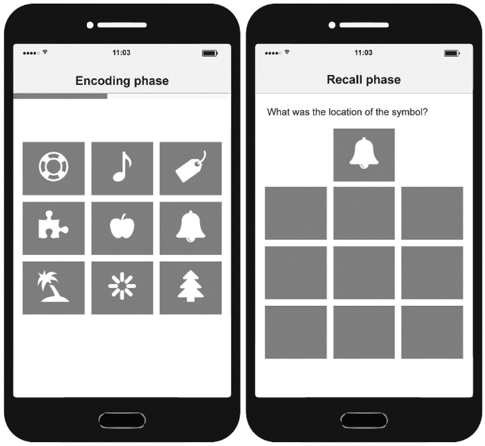
In addition to the beep questionnaires, participants completed a morning assessment and an evening assessment every day, each consisting of seven self-report items. The morning questionnaire focused on self-reported sleep quality. The evening questionnaire focused on a global appraisal of the day. The majority of the items were answered on a seven-point Likert scale (1=not at all, 4=moderate, 7=very). Some items contained categories (e.g. 0, 1, 2, 3, 4, 5, or more than 5 times awake during the night). The full list of ESM items is included in Appendix A.

PsyMate™ momentary Visuospatial Working Memory Task (mVSWMT). The concept of the PsyMate™ mVSWMT is based on the popular card game 'Memory', also known as 'Concentration' or 'Match Match', where players turn cards to find matching pairs. 'Memory' has been used to study concentration and memory functions in various age groups [31, 32]. The mVSWMT aims to measure concentration and visuospatial working memory (i.e., encoding, maintaining, and retrieving visual information). The development team included psychiatric and neuropsychological healthcare professionals as well as ESM researchers. This team defined the following requirements for the mDSST: participants should be able to perform the mobile cognition task several times a day, the task needs to be short, sensitive to cognitive variation, and demonstrates no or a small learning effect.

The participants were instructed that they would see nine icons to remember. After the participant pressed the start button, icons were presented in a three-by-three grid for eight seconds (encoding phase; see left part of Figure 2 a). Next, participants answered two interference questions on a seven-point Likert scale: 'I think I remembered it all', and 'Generally, I feel well at the moment'. During the recall phase (see right part of Figure 2 a), participants were presented with a three-by-three grid of blanc squares with one icon from the original nine above. An instruction stated to select the square of the original location of the presented icon. The selected square revealed the icons underneath to provide feedback. In this first conceptualization, only one trial per beep is provided to keep the ESM assessments as short as possible. Every beep moment, a unique set of symbols was presented. The grids were filled at random from a selection of 122 unique icons (see Figure 2 b) and a random icon cue was selected from the grid. The outcome measure was correct/incorrect (correct =1) during recall. The icons presented in the mVSWMT were chosen as they represent well-known objects of everyday life and are easily recognizable.

PsyMate™ momentary Digit Symbol Substitution Task (mDSST). The PsyMate™ mDSST was inspired by the paper-pencil version of the Digit Symbol Substitution Task (DSST) of the Wechsler Adult Intelligence Scale (WAIS). The original WAIS task measures information processing speed and short-term working memory [33]. The PsyMate™ version aims to measure information processing speed. The mDSST fulfils the momentary task requirements (performable several times a day; short; sensitive to cognitive variation; no/small learning effect) and the same team was consulted during task development.

a)



b)

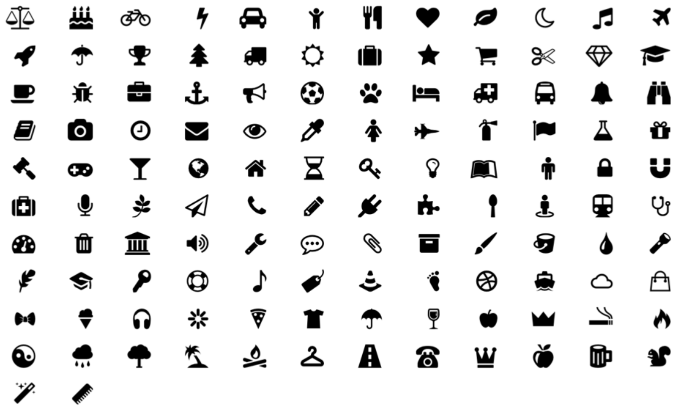


Figure 2. a) PsyMate™ momentary Visuospatial Working Memory Task (mVSWMT) encoding and recall phase. b) Summary of icons presented in the PsyMate™ mVSWMT.

At the end of the regular ESM beep questionnaire, an instruction screen appeared with a start button to be pressed when ready. At the top of the task screen, the numbers 1 to 9 with a corresponding symbol (similar to the WAIS DSST) were displayed for encoding. In the middle of the screen, different numbers were displayed one-by-one for each trial. At the bottom of the screen, participants had to select the symbol that corresponds to the number presented in the middle of the screen (see Figure 3). Within a 30-seconds timeframe, participants had to accurately complete as many trials as possible. The 30-second timeframe was chosen to keep the ESM assessments as brief as possible, thereby minimizing interference during daily routines. While the number-symbol combinations stayed the same during a beep questionnaire, different sets of combinations were used across beeps. In total, ten unique encoding combinations with corresponding answer keys were used at random. Two mDSST outcome measures were computed: the number of trials (speed) and the percentage of correct trials (accuracy).

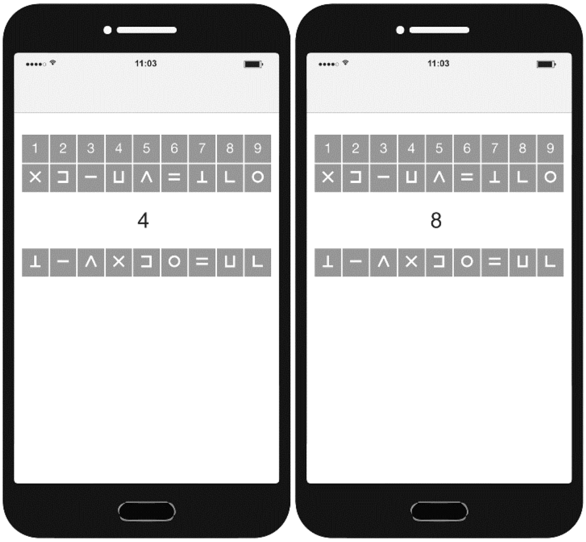


Figure 3. PsyMate™ momentary Digit Symbol Substitution Task.

Debriefing questionnaire

Participants received a debriefing questionnaire that focused on their general experiences during the ESM week (e.g., ‘Was this a normal week?’, ‘Did the PsyMate™ use influence your daily activities?’), the usability of the PsyMate™ (e.g., ‘Were the PsyMate™ instructions clear?’, ‘Was using the PsyMate™ stressful?’), and their experiences with the PsyMate™ mDSST and mVSWMT (e.g., ‘To what extent was the task pleasant to perform?’, ‘Did you experience any technical difficulties?’). Both seven-point Likert scale questions and open-ended questions were used.

Procedure

Following informed consent, a one-hour briefing session took place at Maastricht University or at the participant’s home. Sociodemographic information was gathered (e.g., gender, age, living situation, education level, current occupation, and ethnicity) and additional information was asked on current medication use, earlier treatment for mental illnesses, and cognitive complaints. After these general assessments, either the PsyMate™ was installed on the participant's smartphone device or the participant received an iPod with the latest PsyMate™ version installed. After checking the device settings for battery saving options and allowing push notifications, participants were instructed on how to use the PsyMate™ and the cognition tasks. Test trials were completed to become acquainted with the ESM procedure. Participants started with their six-day ESM period on the following day. During the second day, participants were called to check whether the application was working properly and to clarify potential questions. After the ESM period, a one-hour debriefing session took place during which participants completed the debriefing questionnaire and provided specific feedback with regard to the two cognition tasks.

Statistical analyses

Participant characteristics, feasibility, and acceptability of both cognition tasks were assessed by means of descriptive statistics (frequencies). The completion rate was calculated by comparing the mean percentage of valid beep moments to the total number of beep moments. The data collected with the PsyMate™ have a multilevel structure; beeps (level 1) were nested within participants (level 2). Multilevel regression analyses were used to assess cognitive variation over time and to check for learning effects. The session counter score was used as a proxy measure of time and consists of a sequence of beeps within subjects, ranging from 1 (first beep) up to 48 (last beep). Learning effects were examined by using the session counter to assess the effect over time, hours to assess a within-day time effect and study day (day 1 to 6) to assess a between-day time effect. It is expected that learning will not be linear; therefore, all time variables will be transformed to a logarithmic or quadratic function. Correct/Incorrect (mVSWMT), the number of trials within the 30-seconds time interval (speed), and the percentage of correct trials (accuracy) (mDSST) were used as dependent variables and a log transformation of the session counter (time), hour and its quadratic function, and a log transformation of study day as independent variables. To assess contextualization, dummy variables were created for location (at home vs. somewhere else) and company (alone vs. with others). Activity-related stress was conceptualized as an average of the items 'I would rather be doing something else', 'This is difficult for me', and 'I can do this well' (reverse coded). To assess the association between PA, NA, fatigue, activity-related stress, distraction, worrying, focusing, location, company, and sleep quality as independent variables and the cognition outcomes of the mVSWMT and mDSST as dependent variables, multilevel regression analyses were computed. Covariates in these multilevel models were quadratic age, gender, and possible learning effects as measured with the time variables. In order to investigate age effects, subgroup multilevel regression analyses were performed, splitting participants into a young group (<45 years) and an old group (45 years or older). Furthermore, Fischer-z transformations of by-subject Pearson's pairwise correlations were calculated between the cognitive outcome measures. Analyses were carried out using Stata version 13.0 [34]. A two-sided significance level of .05 was used throughout.

Results

Participants

Seventy-one individuals expressed their interest in the study, of which 66 met the eligibility criteria. From these individuals, seven were not allowed to use mobile phones during work, four individuals did not have enough time, one could not participate because no device was available, and three individuals did not reply after receiving the information. In total, 51 individuals consented to be included, resulting in a 66% recruitment rate.

From the 51 participants who provided informed consent, two participants were excluded because of current treatment for mental health problems. This left data from 49 participants and 1499 beep records. Data of five participants could not be used due to technical problems (beta release of the software: loss of 70 records (4.67%), n=3 transmission problems, n=2 broken devices), leaving a final dataset with 44 participants and 1429 valid beep records. On average, participants completed 34 out of 48 beeps (*SD*=7.03, range 17-47), resulting in a completion rate of 71%. The age of the n=44 participants ranged from 19 to 73 years with a median of 36 years (*M*=40, *SD*=14.82). Sixty-six per cent were women. Highest education level was skewed, with 6% having finished low education, 18% middle education, and 76% high education. Most participants had a fulltime job (61%), others worked part time (23%), studied (7%), took care of their own household (5%), or were retired (4%).

Feasibility

Evaluation of the PsyMate™ procedure

The items represented the participants' experiences well (*M*=5.70, *SD*=1.53), the PsyMate™ was easy to use (reverse coded, *M*=1.25, *SD*=.78), and the verbal and written instructions were clear (respectively *M*=6.86, *SD*=.41; *M*=6.84, *SD*=.48). The PsyMate™ did not influence the participants' mood (*M*=2.11, *SD*=1.53), activities (*M*=1.91, *SD*=1.01), or social contact (*M*=1.91, *SD*=1.18). The number of beeps, duration of a beep, and sound had a low impact on the burden (respectively *M*=3.2, *SD*=1.79; *M*=2.61, *SD*=1.86; *M*=2.32, *SD*=1.62). Three people found the length of the questionnaire too long.

Evaluation of the mVSWMT

Participants reported that the mVSWMT was pleasant to use (*M*=5.05, *SD*=1.57), but rather difficult (*M*=4.61, *SD*=1.79). Six participants indicated that the interference questions between encoding and recall made the task difficult. Participants did not get distracted during the task (*M*=2.93, *SD*=1.53) and were highly motivated to perform well (*M*=5.84, *SD*=1.16). They indicated that they made few inaccuracies (*M*=1.75, *SD*=1.28) and would recommend the task to others (*M*=5.25, *SD*=1.62). They provided some suggestions for further improvement, namely a longer encoding phase and a timer. Participants reported strategies to recall the icons: reading aloud (7 times), creating a story or a mnemonic (6 times), remembering the icons and the location of the icons (5 times), and remembering the first, the middle, or the last row (6 times).

Evaluation of the mDSST

Participants reported that the mDSST was pleasant (*M*=5.66, *SD*=1.22) and easy to use (reverse coded, *M*=1.86, *SD*=.90). They were not distracted during the task (*M*=3.00, *SD*=1.43) and highly motivated to perform well (*M*=5.93, *SD*=1.13). Participants reported that they made few inaccuracies (e.g., tapping symbol X instead of symbol Y) (*M*=3.00, *SD*=1.54). Fourteen people commented that the size of the response buttons was too small, potentially leading to inaccuracies. Participants would recommend the task to others (*M*=5.82, *SD*=1.11). They provided some suggestions for further improvement: to increase the symbol and number size or rotate the screen horizontally. This was especially an issue for iPod users since the screen was smaller.

Contextual factors

Participants experienced high PA (*M*=5.08, *SD*=.69, range 3.35–6.66) and low NA (*M*=1.49, *SD*=.55, range 1.01–3.20). Furthermore, they felt moderately fatigued (*M*=3.01, *SD*=1.19, range 1–5.64), were a little worried (*M*=2.23, *SD*=1.15, range 1–5.43), and experienced low activity-related stress (*M*=2.44, *SD*=.56, range 1.61–3.69). Overall, participants reported a high level of focus during an activity (*M*=4.78, *SD*=.77, range 3.11–6.45) and experienced low to moderate distraction during the mDSST (*M*=2.79, *SD*=.88, range 1.05–4.53). Participants were alone in 29% of the time and in company 71% of the time. Furthermore, they spend 56% of the time at home and 44% somewhere else. According to the morning questionnaire, participants fell asleep after 5 to 15 minutes (40%) and woke up once during the night (34%). Participants slept well (*M*=5.25, *SD*=.80, range 3.46–7) and felt well rested at the start of the day (*M*=4.62, *SD*=1.03, range 2.67–6.65).

Cognition in relation to contextual factors

mVSWMT

Overall, participants were correct in 37% of the mVSWMT assessments (*SD*=.16, range .07–.74). There was no association between time (session counter score) and the mVSWMT outcome, (*B*=.01, *SE*=.01, *p*=.32, 95% CI =-.01, .04), showing no within-day time effect (*B*=-.004, *SE*=.003, *p*=.17, 95% CI=-.01, .002), nor between-day time effect (*B*=.04, *SE*=.03, *p*=.17, 95% CI=-.02, .09), indicating no learning-effect.

Participants made more mistakes when experiencing high PA (*B*=-.03, *p*=.04), when in company (vs. being alone; *B*=-.10, *p*<.001), and when being distracted (*B*=-.03, *p*=.001). Being able to focus during an activity resulted in more correct answers (*B*=.04, *p*<.001). NA, fatigue, activity-related stress, location, worrying, and sleep quality (morning questionnaire) were not associated with the mVSWMT outcome. More mistakes were made with higher age (*B*=-.00005, *p*=.002), whereas gender was not associated. For all results, see appendix B.

To build the final multilevel regression model, a basis of PA, NA, and its interaction effect was extended with variables that were associated with the cognition outcome measure. No interaction effect was found between PA, NA, and the mVSWMT outcome. The effect of PA disappeared and participants again made more mistakes when in company (*B* =-.09, *p*=.002), when distracted (*B*=-.02, *p*=.03), and with older age (*B*=-.00006, *p*<.001). Being able to focus during an activity was associated with more correct answers (*B*=.05, *p*<.001). The results of this analysis indicated that the seven predictors explained 6% of the overall variance (3% within-subject variance and 28% between-subject variance). Results of the final model for correct/incorrect are presented in Table 1.

Table 1**.** Final model of the mVSWMT outcome Correct/Incorrect.

	Correct/incorrect				
	B	SE	p	95% CI	
Model			< .000***		
PA	-.06	.03	.08	-.13,	.01
NA	-.06	.09	.48	-.25,	.12
PA x NA	.01	.02	.33	-.03,	.05
Focus	.05	.01	< .001***	.03,	.07
Company$	-.09	.03	.002**	-.14,	-.03
Distraction	-.02	.01	.03*	-.03,	-.001
Age^2	-.00006	.00002	< .001***	-.00009,	-.00002

Note. PA = positive affect. NA = negative affect. PA x NA = interaction between positive and negative affect. Company$ = dummy variable of being alone versus with others. Age^2 *= quadratic function of age. CI = Confidence Interval. *p < .05, **p < .01, ***p < .001.*

5

mDSST

Due to technical problems, 82 times (5.7%) the mDSST did not follow the ESM questionnaire. These records were removed, leaving a sample of 42 participants with 1347 beep records. Participants completed on average 12 trials (*SD*=2.57, min=7.21, max=16.83) within the 30-second timeframe, with on average 97% accuracy (*SD*=1.81, min=92.29, max=100). Participants completed more trials over time (beep 1 vs. beep 48; *B*=.32, *SE*=.04, *p*<.001, 95% CI=.24, .40), showed no within-day time effect (*B*=.01, *SE*=.01, *p*=.12, 95% CI =-.003, .03), but more completed trials at later study days (*B*=.61, *SE*=.08, *p*<.001, 95% CI=.45, .76). Accuracy was not associated with time (*B*=.08, *SE*=.20, *p*=.71, 95% CI=-.32, .47), showing no within-day time effect (*B*=.05, *SE*=.04, *p*=.25, 95% CI=-.03, .13) nor between-day time effect (*B*=-.02, *SE*=.36, *p*=.96, 95% CI=-.72, .68).

NA, activity-related stress, location, sleep quality, and gender were not associated with either cognitive outcome measure. Looking at speed, participants completed less trials when in company (*B*=-.29, *p*=.001), when being distracted (*B*=-.15, *p*<.001), and with older age (*B*=-.001, *p*<.001). Furthermore, participants completed more trials when worrying (*B*=.09, *p*=.02). PA and being able to focus were not associated with speed. Looking at accuracy, participants made more mistakes when being tired (*B*=-.34, *p*=.007) and with more distraction (*B*=-.54, *p*<.001). Participants made less mistakes when they experienced more PA (*B*=.45, *p*=.03) and when they could focus better (*B*=.36, *p*=.01). Company was not associated with accuracy. For all results, see Appendix C.

Again, the basic model was extended with variables that were associated with the mDSST outcome measures. In the final model of speed (see Table 2), mood showed no effect, and time and worry effects disappeared. Participants completed fewer trials when in company (*B*=-.18, *p*=.04), when being distracted (*B*=-.15, *p*<.001), and with older age (*B*=-.002 *p*<.001). The results of this analysis indicated that the nine predictors explained 48% of the overall variance (8% within-subject variance and 56% between-subject variance).

Table 2**.** Final model of the mDSST Speed Outcome.

	Speed				
	B	SE	p	95% CI	
Model			< .001***		
PA	.04	.11	.74	-.18,	.26
NA	.01	.30	.97	-.57,	.59
PA x NA	-.02	.06	.81	-.14,	.11
Worry	.06	.04	.14	-.02,	.14
Company$^{\$}$	-.18	.09	.04*	-.34,	-.01
Distraction	-.15	.02	< .001***	-.20,	-.10
Age^2	-.002	.0002	< .001***	-.002,	-.001
Time$^{\$}$	.17	.10	.08	-.02,	.37
Study day$^{\$}$	.34	.18	.06	-.02,	.70

Note. PA = positive affect. NA = negative affect. PA x NA = interaction between positive and negative affect. Company$^{\$}$ *= dummy variable of being alone versus with others. Age*^{2} *= quadratic function of age. Time*$^{\$}$ *= log-transformed session counter score. Study day*$^{\$}$ *= log-transformed day of study score. CI = Confidence Interval. *p < .05, **p < .01, ***p < .001.*

In the final model of accuracy (see Table 3), the effect of fatigue and PA disappeared and no other mood effects were found. Participants made more mistakes when being distracted (*B*=-.51, *p*<.001). The results of this analysis indicated that the six predictors explained 3% of the overall variance (2% within-subject variance and 20% between-subject variance).

Young vs. older age and cognition

In order to gain more insight into age effects, exploratory subgroup analyses were performed for both cognition tasks. Splitting age groups for the mVSWMT data resulted in n=26 (59%) in the young group (<45 years) and n=18 (41%) in the older age group (45 years or older). In both groups, being able to focus resulted in more correct answers (young age: *B*=.05, *p*<.001; older age: *B*=.04, *p*=.01). However, in the older group, participants made more mistakes when being in company (*B*=-.13, *p*=.001) and with increasing age (*B*=-.00007, *p*=.047).

With the mDSST data, data from two participants were excluded due to technical problems (see section 3.4.2), leaving n=26 in the young group (62%) and n=16 in the older age group (38%). Results for speed remained largely the same in both groups, showing a main effect of distraction with higher distraction resulting in fewer trials. A similar result was found in both groups for accuracy, where higher distraction resulted in more mistakes. The difference was that the younger group completed more trials over time (*B*=.30, *p*=.047). The older group did not show a time effect on number of beeps (log-transformed session counter score), but completed more trials over study days (*B*=.47, *p*=.02) and when PA was higher (*B*=.33, *p*=.04). In addition, fewer trials were completed when being in company (*B*=-.22, *p*=.02), and with increasing age (*B*=-.001, *p*<.001) within the older group but not the younger group. Results of the subgroup analyses are presented in Appendix D.

Table 3. Final model of the mDSST Accuracy Outcome.

	Accuracy				
	B	SE	p	95% CI	
Model			< .001***		
PA	-.22	.50	.67	-1.19,	.76
NA	-1.15	1.28	.37	-3.66,	1.36
PA x NA	.25	.28	.37	-.30,	.81
Fatigue	-.22	.14	.13	-.50,	.06
Focus	.14	.15	.34	-.15,	.44
Distraction	-.51	.11	< .001***	-.72,	-.30

*Note. PA = positive affect. NA = negative affect. PA x NA = interaction between positive and negative affect. CI = Confidence Interval. *p < .05, **p < .01, ***p < .001.*

Correlations between mVSWMT and mDSST

Fisher-z transformations of by subject pairwise correlations were used between the mVSWMT outcome correct/incorrect, and the mDSST outcomes speed and accuracy. Over subject averages, there were no significant correlations between correct/incorrect and speed (*z*=1.36, *p*=.09), nor accuracy (*z*=-0.35, *p*=.64).

Discussion

Feasibility of the momentary cognition tasks

This study confirms the feasibility of two newly developed momentary cognition tasks within the PsyMate™ app in healthy individuals. The completion rate was high (71%) and is in line with other ESM studies with and without cognition tasks [35, 36]. Furthermore, participants overall experienced the cognition tasks as pleasant and were motivated to perform well.

Although entertaining, the mVSWMT was experienced as difficult. In only 37% of the mVSWMT assessments the icon location was remembered correctly, with a range from 7% to 74% between participants. Differences may reflect the use of strategies, such as thinking of an ‘icon-story’ or trying to group the icons per row. In other momentary visuospatial working memory studies, participants identified the correct location(s) in 90% of their responses [37-39]. In these studies, neutral circles in a grid were presented while meaningful icons were used in the mVSWMT (see Figure 3 b). Remembering the location combined with the meaning of the icon requires a higher cognitive demand. The choice for the here-used icons was made to test a greater working memory capacity [30, 40]. Furthermore, the meaningful icons were expected to motivate the participant, which was confirmed by the positive feedback. Participants responded randomly on the interference items to perform better on the mVSWMT. Prospectively a different interference [39] should be considered. For example, a fixed timer could be applied to standardize the interference between encoding and recall.

In contrast, participants experienced the mDSST as easy, which resulted in a ceiling effect for accuracy (97% correct). This high accuracy is in line with another digital processing speed task named the Colour-Shape Test, where participants answered correctly in 97% of the attempts [41]. In the paper-pencil DSST version, participants also make little mistakes reflected by a high accuracy, while the speed outcome proves more sensitive to cognitive variations [33]. The mDSST speed performance varied between and within subjects, which indicates this outcome to be suitable in detecting momentary cognitive fluctuations.

These feasibility results confirm that both tasks are appropriate, but need fine-tuning. For instance, the font size could be increased or the screen rotated to further improve the mDSST. Nevertheless, some limitation need to be acknowledged. In the mVSWMT analyses, the position of the icons could not be taken into account due to technical limitations. Descriptive background analysis revealed that a slight primacy and recency effect appeared, as participants remembered the first or last icons slightly more often. The discrepancy between identified location and actual location may be an interesting aspect of a momentary working memory task in the future. Additionally, the sample was healthy and highly educated resulting in limited generalizability of the feasibility results. Next steps may include testing the adjusted mDSST and mVSWMT in a more diverse healthy and clinical populations.

Validity of momentary cognition tasks through contextualization

Initial evidence for the validity of the momentary cognition tasks was provided by relating cognitive performance with intrapersonal factors (e.g., mood, fatigue, stress, sleep-related outcomes) and contextual factors (e.g., being in company of others) to evaluate and understand momentary cognitive performance. Surprisingly, mood and fatigue had no effect on cognitive performance. One explanation could be that the participants were healthy, well rested, and overall in a positive mood. Timmers et al. (2014) also found no indication for an effect of fatigue on cognition (i.e., short-term memory) in healthy young adults [42]. Previous findings on the relation between mood and cognition in daily life are inconclusive. While one study found no association between changes in mood and cognitive functioning [43], another study reported that higher positive mood resulted in less interference during an emotional Stroop task[44]. Stronger associations may appear in clinical populations [45, 46].

Individual performance on the mVSWMT and mDSST was diminished when distracted and in social company. Logically and confirmed by experiments, distraction has a negative influence on cognitive performance [47]. The negative influence of being in company was also previously reported: Von Stumm (2018) argues that being alone may help to focus one's attention and thus improve cognitive performance. In contrast, it cannot be assumed that social context truly lowers a person's cognitive ability. This result may rather be related to variations in situational demands [43]. In the present study, participants were in company in 71% of the time. Hence, future studies may take the potentially mediating factors of company and distraction into account when analysing momentary cognitive fluctuations.

Age sensitivity was found for both tasks with associations between age and visuospatial working memory and processing speed in everyday life. As expected [48], younger adults performed better. It is important to disentangle the cognitive decline in performance from an assessment bias. Compared to younger adults, older adults tend to experience technologies as less easy to use [49]. Additionally, older adults may have impaired hearing or vision, potentially affecting the usability and thus outcomes of technology-based assessments. Previous studies, however, confirmed the feasibility, reliability, and validity of digital assessments in the elderly [41, 50, 51]. All participants became better over time, but the learning curve was steeper for younger adults than for older adults. Learning effects were reported in previous mobile cognition tasks and may not affect sensitivity negatively [51]. Descriptive background analysis revealed that learning stabilized after 10 to 15 beeps and a steady state is reached within the first days of the study.

The non-significant correlation between the two momentary tasks suggests that different cognitive domains are measured, namely processing speed (mDSST) and visuospatial working memory (mVSWMT). This finding is in line with previous research that also found no correlation between momentary working memory and processing speed, possibly due to the unreliability of one task [43]. Strategy use was different between the two momentary tasks in this study. The lack of correlation could be due to a different approach in both tasks, hindering a comparison of cognitive performance per se. It is expected that the current tasks will correlate after adjustment are made and when tested in a clinical sample with cognitive complaints. If no correlation shows, it might be that strategy use is moderating cognitive performance.

The present validation study did not focus on correlations with traditional neuropsychological tests. However, an in-house (unpublished) trial with 50 healthy participants showed that outcomes of a two-minute mDSST and paper-pencil DSST correlated (partial r=.50, p<.001). Participants reported that the digital version was slightly more difficult, as learning the digit-symbol combinations was challenging and the next number could not be anticipated. This preliminary finding provides initial evidence that the 30-second mDSST measures processing speed, but needs extension to confirm construct validity.

Overall, these validity findings can be seen as a proof of concept for the contextualization of momentary cognitive performance. Future research is needed to disentangle the complex interaction between mood, context, and cognition further. In addition, limitations include not taking the education level and the relation with traditional neuropsychological tests into account as part of the validation. Furthermore, the developed tasks are still artificial [13], in the sense that individuals normally do not perform these tasks, but actually search for their keys or process information to plan their days.

Next steps are the final adjustments of the app and testing both tasks in populations with different cognitive profiles. Clinical populations may include people with schizophrenia, major depression, or brain damage. Furthermore, situations that influence the cognitive performance such as tiredness, alcohol use, or medication intake may provide relevant insight into the validity of the tasks. Cognitive assessments in everyday life, in combination with momentary sampling of mood and context, may prospectively give individuals more insight into their functioning and thus support self-management and planning. This study is an important step in the anticipated personalization of holistic mobile health [12].

Suggestions for future development and use of momentary cognition tasks

Reflecting on the overall development and use of the mDSST and mVSWMT, a number of lessons were learned and can be implemented in future studies (see Table 4). Most momentary cognition tasks are inspired by traditional neuropsychological tests. For example, in addition to the DSST used as reference in the present study or by Suffoletto et al. (2017) [52], other studies used momentary processing speed tasks based on the Trail B test or the Stroop task [45, 53]. Furthermore, the laboratory n-back task assessing working memory capacity has been adapted to fit into a momentary approach [54-57]. A direct translation can be problematic due to the variability of everyday life that needs repeated assessments in complex environments. Smartphone assessments can offer new possibilities for task development and use. Furthermore, input from a multi-disciplinary team involving neuropsychological healthcare professionals and ESM experts should guide the development. Other stakeholders, including clinicians and patients, should be consulted during development and evaluation. The participant's self-report and observations of the technology use (Chapter 2) [58] can provide insights into their perspective and experience when measuring momentary cognition within an ESM paradigm. Gamification is a strategy to increase motivation. An example of gamification to measure cognition is the Sea Hero Quest smartphone app (www.seaheroquest.com). Participants orient themselves in a virtual sea world and get rewards when performing well. This quest may be a valid method to assess navigation skills in a fun way [59], however, it may be less suited for clinical practice were repeated assessments of cognitive performance are interwoven with assessments of mood and context. It is important to strike a balance between a thoughtful completion of the ESM items and the competitiveness and enjoyment of a cognitive performance task.

Testing the cognition task in a healthy sample is a useful way to test feasibility and validity [37, 42]. Adjustments can be made before introducing the task to a more vulnerable clinical population. A benefit of ESM is that individuals can be their own controls and performance can be compared within one dataset [14, 60].

Another aspect to consider is the beep frequency. While a high intensity may reveal more fluctuations, beep length and time investment need to be considered. The strength of a good ESM questionnaire lies in the intuitiveness of assessments and it is very important that users are able to complete the questionnaires without over thinking the answers and with minimal interference to their usual routine [60]. Adding a cognition task should not change the adherence to good ESM practice. When assessments are made repeatedly and in the flow of daily life, the beep length should not exceed a couple of minutes to prevent interference. Potentially, tasks can alternate at random across assessments to minimize fatigue effects. In general, participant's experience should be explored and if necessary, guide task adjustments when feelings of over- or under stimulation appear. Task difficulty may be tailored to the individual's ability. Working memory tasks with varying levels of difficulty have been tested in other ESM tools [52, 61]. Ideally, momentary assessment promotes a flow in everyday life. Tasks should remain challenging when users reach a level of experienced achievement that relates to the individual's overall cognitive ability (e.g., being correct in 70% of the cases). The right difficulty level can prevent a loss of motivation and simultaneously preclude frustration or even resentment [62, 63]. Prospectively, studies may consider automatically adjusting the level based on an individual's performance.

When implementing momentary cognition tasks, the sampling duration needs to be tailored to the research or clinical question [60]. Examples include single case assessments running over months or years, where continued experience sampling can illustrate useful insight into the course of a disease [64, 65]. In the assessment process at memory clinics, weeklong momentary cognition tasks can supplement traditional neuropsychological test batteries and provide information on cognitive fluctuations in everyday life [50]. Side effects of new medications may furthermore be detected when using momentary cognition tasks parallel to the dose adjustments of drugs [54]. Finally, in rehabilitation centres, e.g., after brain damage, momentary cognition tasks may determine the effectiveness of the treatment when applied before and after a program. Insight into momentary cognitive fluctuations in context can be used to provide individuals with feedback and guidance to deal with cognitive complaints in daily life.

Table 4. Suggestions for future task development and use.

Suggestions for Momentary Cognition Tasks	
Task **Development**	Task **Use**
• Involve a multi-disciplinary team • Orientate concepts on traditional neuropsychological tests • Balance enjoyment/gamification with context information (experiences and physical context) • Ideal outcomes need to show clinically relevant within- and between-subject variance, be age-sensitive, and show no ceiling-effect • Use comparison data to determine between-subject variance; within-subject data serves as its own control	• Tailor beep frequency and sampling duration to the research/clinical question • Balance length and number of tasks, and additional momentary items • Limit assessment time (e.g., 2 minutes) • Adjust difficulty levels to individual abilities to prevent frustration and maintain motivation • Consider momentary context during interpretation (e.g. distraction) • Consider learning-effects (particularly in early trials)

Conclusions

Momentary cognition tasks aim to depict fluctuation of cognitive performance in everyday life and hold promise for future research and clinical use. Prospectively, the task application needs to be extended, for example into different cognitive domains or patient populations. Furthermore, the interaction with other intrapersonal factors requires further disentanglement. Next steps can be guided by the suggestions resulting from this study such as involving a multi-disciplinary team, tailoring the set-up to the individual, and balancing the level of enjoyment and seriousness.

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Supplementary Material

Appendix A

Table A.1 Experience Sampling Protocol: Beep Questionnaire.

	Item	7-point Likert scale or categorical options
1	I feel cheerful	1 = not at all 4 = moderate 7 = very much
2	I feel energetic	1 = not at all 4 = moderate 7 = very much
3	I feel insecure	1 = not at all 4 = moderate 7 = very much
4	I feel relaxed	1 = not at all 4 = moderate 7 = very much
5	I feel down	1 = not at all 4 = moderate 7 = very much
6	I feel irritated	1 = not at all 4 = moderate 7 = very much
7	I feel satisfied	1 = not at all 4 = moderate 7 = very much
8	I feel lonely	1 = not at all 4 = moderate 7 = very much
9	I feel enthusiastic	1 = not at all 4 = moderate 7 = very much
10	I feel anxious	1 = not at all 4 = moderate 7 = very much
11	I feel guilty	1 = not at all 4 = moderate 7 = very much
12	I'm worrying about things	1 = not at all 4 = moderate 7 = very much
13	mVSWMT instruction screen	
	mVSWMT part 1: encoding	
14	I think I remembered it all	1 = not at all 4 = moderate 7 = very much
15	I generally feel well at the moment	1 = not at all 4 = moderate 7 = very much
16	mVSWMT instruction screen	
	mVSWMT part 2: recall	
17	What am I doing (right before the beep)	work, school/housekeeping/self-care/relaxing/sport, movement/eating, drinking /traveling, on the road/ having a conversation/something else/nothing
18	I can do this well	1 = not at all 4 = moderate 7 = very much
19	This is difficult for me	1 = not at all 4 = moderate 7 = very much
20	I would rather be doing something else	1 = not at all 4 = moderate 7 = very much
21	I am focused	1 = not at all 4 = moderate 7 = very much
22	Where am I (just before the beep)	at home/at someone else's home/work, school/public space/on the road/somewhere else
23	Who am I with (just before the beep)	partner/family/housemates/friends/colleagues/ acquaintances/strangers, others / nobody
24a	Company: I like this company	1 = not at all 4 = moderate 7 = very much
25a	Company: I would rather be alone	1 = not at all 4 = moderate 7 = very much
24b	Alone: I like being alone	1 = not at all 4 = moderate 7 = very much
25b	Alone: I would rather be in company	1 = not at all 4 = moderate 7 = very much
26	I don't feel well	1 = not at all 4 = moderate 7 = very much
27	I am tired	1 = not at all 4 = moderate 7 = very much

Table A.1 Continued

	Item	7-point Likert scale or categorical options
28	Since the last beep I have used	alcohol/medication/coffee, caffeine/smoking, nicotine/ cannabis/other drugs/nothing
29	mDSST instruction screen	
	mDSST	30-seconds timeframe
30	I got distracted during the task	1 = not at all 4 = moderate 7 = very much
31	This beep disturbed me	1 = not at all 4 = moderate 7 = very much
31	Thanks!	

Table A.2 Experience Sampling Protocol: Morning questionnaire.

	Item	7-point Likert scale or categorical options
1	I generally felt well today	1 = not at all 4 = moderate 7 = very much
2	I generally felt tired today	1 = not at all 4 = moderate 7 = very much
3	I generally felt tense today	1 = not at all 4 = moderate 7 = very much
4	I generally worried a lot today	1 = not at all 4 = moderate 7 = very much
5	I generally could concentrate well today	1 = not at all 4 = moderate 7 = very much
6	I generally felt forgetful today	1 = not at all 4 = moderate 7 = very much
7	Goodnight!	1 = not at all 4 = moderate 7 = very much

Table A.3 Experience Sampling Protocol: Evening questionnaire.

	Item	7-point Likert scale or categorical options
1	How long did it take before I fell asleep last night?	0 - 5 minutes/5 - 15 minutes/15 - 30 minutes/ 30 - 45 minutes/ 45 minutes - 1 hour/ 1 - 2 hours/ 2 - 4 hours/ > 4 hours
2	How often did I wake up last night?	0/1/2/3/4/5/> 5
3	How long did I lie awake this morning before getting up?	0 - 5 minutes/5 - 15 minutes/15 - 30 minutes/ 30 - 45 minutes/ 45 minutes - 1 hour/ 1 - 2 hours/ 2 - 4 hours/ > 4 hours
4	I slept well	1 = not at all 4 = moderate 7 = very much
5	I feel well rested	1 = not at all 4 = moderate 7 = very much
6	I am looking forward to this day	1 = not at all 4 = moderate 7 = very much
7	Thanks!	1 = not at all 4 = moderate 7 = very much

Appendix B

Table B. Individual Multilevel Regression Analyses of Mood, Context, and Sleep Quality on the mVSWMT outcome Correct/Incorrect.

	Correct/Incorrect				
	B	SE	p	95% CI	
Positive affect	-.03	.02	.04*	-.06,	-.001
Negative affect	-.0003	.03	.99	-.05,	.05
Worry	.002	.01	.89	-.02,	.02
Fatigue	-.01	.01	.54	-.02,	.01
Focus	.04	.01	<.001***	.02,	.06
Activity-related stress	-.01	.01	.49	-.03,	.02
Company$	-.10	.03	<.001***	-.16,	-.05
Location$	-.02	.03	.38	-.07,	.03
Distraction	-.03	.01	.001**	-.04,	-.01
Time until sleep	.01	.01	.23	-.01,	.04
Number of wake-ups	-.005	.01	.67	-.03,	.02
Slept well	.01	.01	.47	-.01,	.03
Well rested	.005	.01	.65	-.02,	.03
Age^2	-.00005	.00002	.002*	-.00009,	-.00002
Gender	-.04	.05	.47	-.14,	.06

Note. Company$ = dummy variable of being alone versus with others. Location$ = dummy variable of being at home versus somewhere else. Age^2 = quadratic function of age. CI = Confidence Interval. **p* < .05, ***p* < .01, ****p* < .001.

Appendix C

Table C. Individual Multilevel Regression Analyses of Mood, Context and Sleep Quality on the mDSST Outcomes Speed and Accuracy.

	Speed					Accuracy				
	B	SE	p	95% CI		B	SE	p	95% CI	
PA	-.01	.05	.90	-.11,	.10	.45	.21	.03*	.03,	.87
NA	-.05	.10	.61	-.24,	.14	-.39	.34	.25	-1.04,	.27
Worry	.09	.04	.02*	.01,	.17	-.20	.15	.17	-.50,	.09
Fatigue	-.02	.03	.46	-.09,	.04	-.34	.12	.007**	-.58,	-.09
Focus	.02	.03	.50	-.04,	.08	.36	.14	.008**	.09,	.63
Act-stress$^{\$}$	.05	.04	.18	-.03,	.13	-.14	.18	.44	-.48,	.21
Company$^{\$}$	-.29	.09	.001**	-.46,	-.12	-.003	.39	.99	-.77,	.76
Location$^{\$}$	-.09	.08	.26	-.25,	.07	.34	.36	.34	-.36,	1.05
Distraction	-.15	.02	<.001***	-.20,	-.10	-.54	.41	<.001***	-.74,	-.33
Time-sleep$^{\$}$	-.04	.04	.32	-.11,	.04	-.07	.17	.67	-.40,	.25
Wake-ups$^{\$}$	-.01	.04	.82	-.08,	.07	-.08	.16	.63	-.40,	.24
Slept well	-.01	.04	.84	-.08,	.07	-.16	.17	.35	-.49,	.17
Well rested	.01	.04	.86	-.07,	.08	.08	.16	.62	-.24,	.40
Age^2	-.001	.0002	<.001***	-.002,	-.001	.0002	.0002	.47	-.0003,	.0006
Gender	.47	.85	.58	-1.19,	2.14	.71	.58	.23	-.44,	1.85

Note. PA = positive affect. NA = negative affect. Act-stress$^{\$}$ = activity-related stress. Company$^{\$}$ = dummy variable of being alone versus with others. Location$^{\$}$ = dummy variable of being at home versus somewhere else. Time-sleep$^{\$}$ = time until sleep. Wake-ups$^{\$}$ = number of wake-ups at night. Age^2 = quadratic function of age. CI = Confidence Interval. *p < .05, **p < .01, ***p < .001.

APPENDIX D

Table D.1 Subgroup Analyses on Age for the mVSWMT Outcome Correct/Incorrect.

	< 45 years of age				
	B	SE	p	95% CI	
Model			< .001***		
PA	-.08	.05	.08	-.18,	.009
NA	-.10	.11	.36	-.32,	.12
PA x NA	.02	.03	.56	-.04,	.07
Focus	.05	.01	< .001***	.02,	.08
Company$	-.05	.04	.21	-.13,	.03
Distraction	-.02	.01	.11	-.04,	.004
Age²	-.00005	.00009	.55	-.0002,	.0001

Note. PA = positive affect. NA = negative affect. PA x NA = interaction between positive and negative affect. Company$ = dummy variable of being alone versus with others. Age² = quadratic function of age. CI = Confidence Interval. **p* < .05, ***p* < .01, ****p* < .001.

Table D.2 Subgroup Analyses on Age for the mDSST Speed Outcome.

	< 45 years of age					45 years or older				
	B	SE	p	95% CI		B	SE	p	95% CI	
Model			<.001***					<.001***		
PA	-.05	.17	.77	-.37,	.28	.33	.16	.04*	.02,	.63
NA	-.27	.39	.49	-1.04,	.49	1.01	.53	.06	-.02,	2.05
PA x NA	.03	.09	.74	-.14,	.20	-.17	.11	.10	-.38,	.04
Worry	.10	.06	.10	-.02,	.21	-.01	.05	.78	-.12,	.09
Company$	-.17	.13	.20	-.43,	.09	-.22	.09	.02*	-.40,	-.03
Distraction	-.19	.04	<.001***	-.26,	-.13	-.08	.03	.004**	-.13,	-.02
Age²	-.0007	.001	.57	-.003,	.002	-.001	.0003	<.001***	-.002,	-.0008
Time$	.30	.15	.047*	.004,	.59	.009	.11	.94	-.21,	.23
Study day$	.24	.28	.40	-.31,	.78	.47	.21	.02	.07,	.88

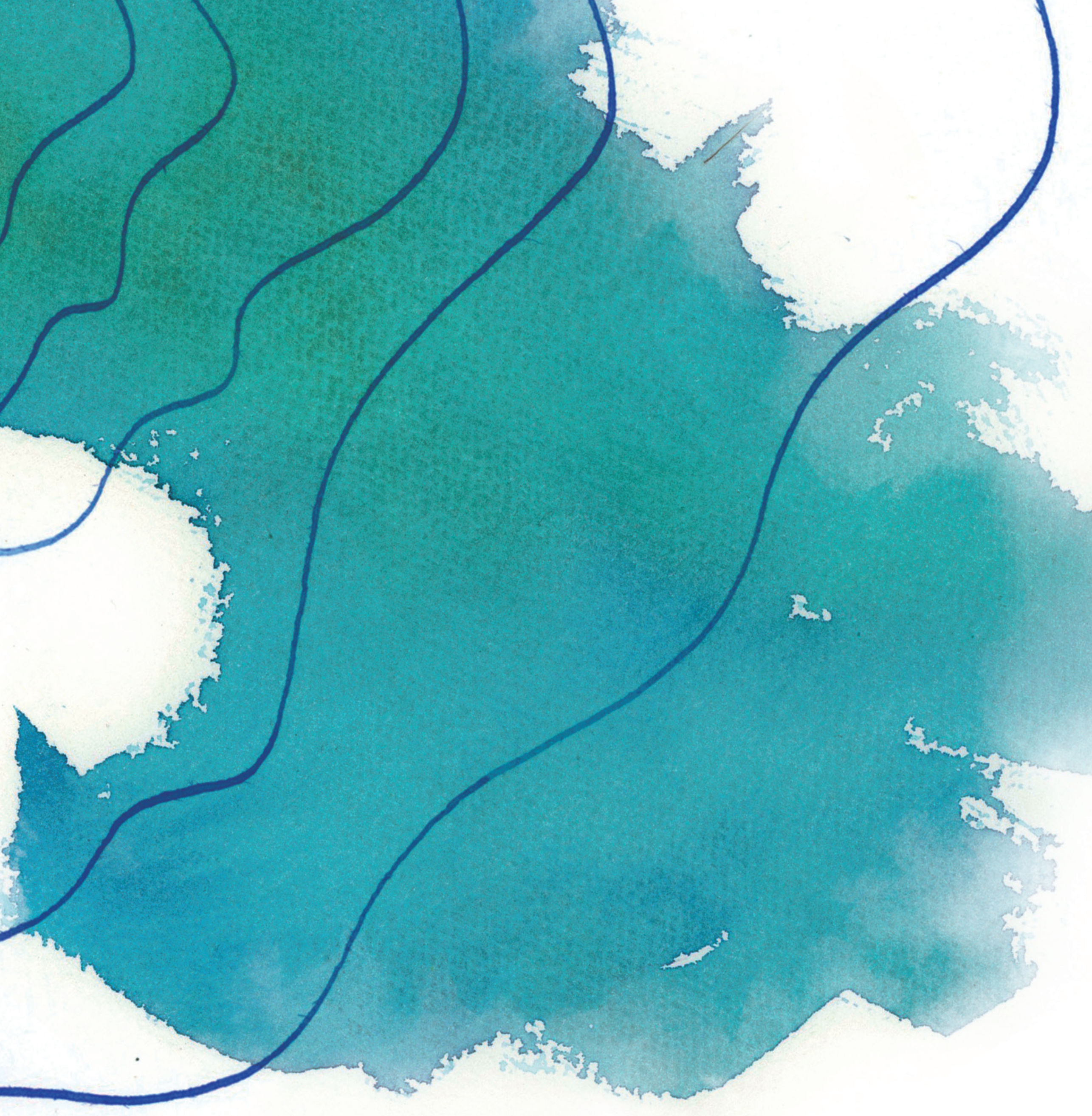
Note. PA = positive affect, NA = negative affect. PA x NA = interaction between positive and negative affect. Location = dummy variable of being at home versus somewhere else. Company$ = dummy variable of being alone versus with others. Age² = quadratic function of age, Time$ = log-transformed session counter score. Study day$ = log-transformed day of study score. CI = Confidence Interval. **p* < .05, ***p* < .01, ****p* < .001.

	45 years or older				
	B	SE	p	95% CI	
			< .001***		
	-.01	.06	.88	-.14,	.12
	.11	.22	.62	-.32,	.54
	-.03	.04	.55	-.11,	.06
	.04	.02	.01**	.008,	.07
	-.13	.04	.001**	-.21,	-.05
	-.01	.01	.22	-.04,	.009
	-.00007	.00004	.047*	-.0001,	-1.13e-06

Table D.3 Subgroup Analyses on Age for the mDSST Accuracy Outcome.

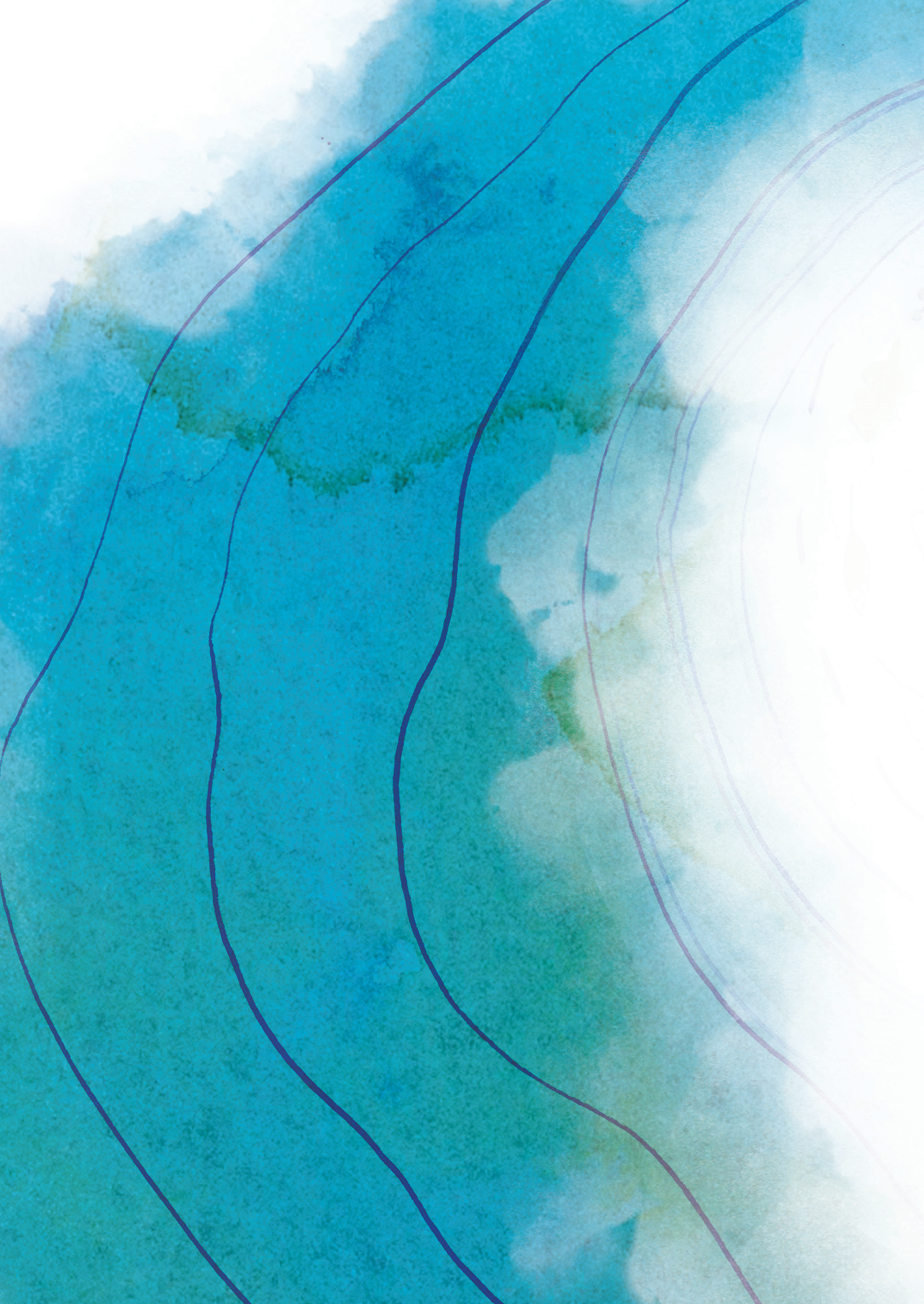
	< 45 years of age					45 years or older				
	B	SE	p	95% CI		B	SE	p	95% CI	
Model			.004**					.003**		
PA	-.86	.68	.21	-.2.18,	.47	.88	.91	.34	-.91,	2.67
NA	-1.92	1.57	.22	-5.004,	1.15	1.11	3.11	.72	-4.98,	7.20
PA x NA	.37	.36	.30	-.34,	1.08	-.15	.61	.80	-1.36,	1.05
Fatigue	-.34	.20	.10	-.74,	.06	-.08	.20	.70	-.47,	.31
Focus	.25	.21	.23	-.15,	.65	-.02	.22	.93	-.45,	.41
Distraction	-.44	.15	.003**	-.73,	-.15	-.57	.16	<.001***	-.88,	-.27

Note. PA = positive affect. NA = negative affect. PA x NA = interaction between positive and negative affect. CI = Confidence Interval. *p < .05, **p < .01, ***p < .001.



Part II

Interventions & Effectiveness



Chapter 6

A Narrative Synthesis Systematic Review of Digital Self-Monitoring Interventions for Middle-Aged and Older Adults

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Internet Interventions (2019)

Abstract

Objective: Self-monitoring is crucial to raise awareness for own behaviours and emotions, and thus facilitate self-management. The composition of self-monitoring within interventions, however, varies and guidelines are currently unavailable. This review aimed to provide a comprehensive overview of technology-based self-monitoring interventions that intend to improve health in middle-aged and older adults (>45 years).

Methods: Five online databases were systematically searched and articles were independently screened. A narrative synthesis of 26 studies with 21 unique interventions was conducted. Primary focus lay on the composition of self-monitoring within interventions, including technology used, health-aspects monitored, and type of feedback provided. Secondly, the usability of/adherence to the self-monitoring treatment, intervention effects, and their sustainability were examined.

Results: Studies concentrated on middle-aged adults (mean of 51 years). Mobile technologies seem necessary to ensure flexible self-monitoring in everyday life. Social health aspects were rarely monitored. Mechanisms and the sustainability of intervention effect are understudied.

Conclusion: Digital self-monitoring technologies hold promise for future trials as they seem suitable to understand and support health-related self-management. Key elements including automatic and personal feedback following the blended care principle were highlighted and may guide study designs. Prospectively, research is especially needed to study sustained self-monitoring to support disease prevention and lasting lifestyle changes.

Introduction

Self-monitoring is known to be a crucial element of health promotion and disease prevention [1]. Social cognitive theory states that self-monitoring influences a person's motivations and actions as it increases attention towards his/her own behaviours, their occurrence and effects; therefore, the success of self-management depends on the fidelity, consistency and temporal proximity of self-monitoring [2].

In clinical settings, the monitoring of patients generally occurs periodically. For instance, the average number of medical visits in older Europeans was 7.75 per year per person [3]. As the contact is only periodical, individuals tend to be self-responsible during most of their life when it comes to own health-management. Furthermore, self-reports during the visits to doctors happens retrospectively due to the type of questions asked in questionnaires (e.g. *"How has your mood been in the past four weeks?"*).

More and more innovative eHealth solutions are available for healthcare professionals to support their patients outside of periodical face-to-face sessions and clinicians have overall positive attitudes towards eHealth [4]. Digital self-monitoring, for instance, has the potential to address and promote health in an individual's daily life. A benefit of the digital momentary self-monitoring approach is the high ecological validity, as information is gathered in an individual's natural rather than artificial clinical or laboratory environment [5]. Furthermore, reporting experiences in the moment in which they occur (e.g. "*How enthusiastic are you right now?")* reduces any potential memory bias, which is frequently found in retrospective assessments [6]. Repeated demonstration of self-reports over days or month displays a heterogeneously fluctuating picture of behaviours and experiences [7] and allows for the exploration of temporal relationship between variables.

The Experience Sampling Method and Ecological Momentary Assessment

Diary methods such as the experience sampling method (ESM) [8, 9] or the ecological momentary assessment (EMA) [10] offer repeated momentary data-collection situated in daily life and can be utilized in health-related self-monitoring. These approaches provide insight on how individuals think, feel, and behave on a daily basis. At multiple time points, individuals can provide systematic self-reports via (digital) diaries on their behaviours as well as experiences by filling in short questionnaires on smartphone apps or mobile devices. The collection of these reports makes it possible to represent the complex relations between psychological, physiological, and social functioning, and current context (e.g. location, activities, and social company). These momentary self-reports are commonly prompted by the technology through, for example, auditory signals (beeps) at predefined time-intervals (time-sampling) but can, in some cases, also be self-initiated by the individual when a particular event occurs (event-sampling) [11].

In the present study, the term 'self-monitoring' includes all forms of *active* ambulatory assessments and therefore represents an intersection between both ESM and EMA. Active self-monitoring requires the person to reflect on and evaluate the situation and, thus, needs to be distinguished from passive self-monitoring, where (physical) functioning is recorded automatically (e.g. fitness or smart watches).

Self-monitoring within interventions

ESM and EMA have traditionally been used to describe and understand disease patterns. Beyond that, researchers and clinicians have integrated real-life data collections in recent decades in intervention approaches with the aim of improving certain aspects of health and modify behaviour. Reviews have described the approach as effective to improve health, for example, in serious mental illnesses [12, 13] or alcohol use disorders [14, 15]. Heron & Smyth (2010) emphasize that *digital* self-monitoring via mobile technologies such as smartphone apps or hand-held computers seem to be particularly promising in providing psychosocial and health behaviour treatment [16]. A digital approach is furthermore cost-effective and can provide support in situations when it is most needed [17, 18].

At the moment, the composition of the self-monitoring in interventions varies strongly between studies. Components seem to differ such as the technology used, intervention duration, follow-up period, amount and intensity of self-monitoring per day, health aspects monitored, and additional features such as personal or automatic feedback. When wishing to work with a self-monitoring approach to support a person's treatment, general guidelines are unavailable and this diversity complicates the clinicians' decision-making process on how to best structure the intervention.

To our knowledge, no recent review is available focusing on *digital* self-monitoring and its use for health promotion in middle-aged and older adults. Cain, Depp, & Jeste (2009) assessed the feasibility and application of ecological momentary assessments in psychological and behavioural research on aging over ten years ago [19]. More recent reviews focus on technological solutions for specific health issues in older adults such as chronic conditions [20], or physical activity [21], while the composition of self-monitoring in interventions has not been prioritized yet. In the current aging world, it is particularly important to find the best way to treat and prevent diseases in these populations as they experience a variety of health issues [22, 23].

Review objectives

This systematic review aims to provide a comprehensive overview of digital self-monitoring interventions that intend to improve health in middle-aged and older adults.

The primary focus lies on describing (1) the composition of ESM/EMA self-monitoring interventions. This evaluation includes the technology used for the active self-monitoring, (physical, emotional, social) components monitored, intensity and duration of ESM/EMA, if and what kind of feedback was provided, and which other intervention elements were part of the setup. The second focus lies on describing (2) the usability, adherence to the treatment, the intervention effects, and their sustainability. Identified key elements will be discussed and are expected to inspire and guide future digital self-monitoring interventions. Possibilities and challenges will be debated to illustrate digital self-monitoring as a means to promote a lasting healthy lifestyle and thus contribute to prevention of diseases in middle-aged and older adults.

Methods

This systematic review was registered on PROSPERO under the registration number CRD42018100649.

Search strategy

In April 2018, the bibliographic databases PubMed, PsycINFO, CINAHL, Web of Science, and Cochrane Library were systematically searched to identify studies reporting on intervention approaches using digital self-monitoring (ESM/EMA) with the intention to improve health. Therefore, the following terms were used when searching the database: 'intervention', 'ESM'/'EMA', 'technology', and 'health'. Appendix A presents the complete search strategy. To find indexed as well as non-indexed articles, MeSH terms, Thesaurus terms, and also non-MeSH terms were included. The resulting reference lists were reviewed to identify additional relevant articles (e.g. through back citation) for potential inclusion. Manuscripts published between 2007 and April 2018 were included in this review.

Study selection

The identified citations were imported into EndNote and de-duplicated. The reviewers (SB, RvK, FD) read the abstracts and full-texts independently. Every abstract and full-text was read twice. SB and RvK performed the abstract scanning, while SB and FD read the full-text manuscripts. If consensus whether to in-/exclude a study into the review could not be reached between SB and RvK/FD, MdV was consulted as a third reviewer to make the final decision on in-/exclusion of a study.

Inclusion criteria

A study was included if it met the following criteria: (1) applying ESM/EMA defined as active real-life data collection of at least two out of three health aspects (physical, emotional, and social) with self-monitoring on at least three days in one week; (2) using technology for the self-monitoring; (3) aiming to promote health within an intervention; (4) in middle-aged or older adults. 'Middle-age' was here defined as populations with a mean age of 45 years and older (rounded up from 44.5 years).

Self-monitoring of at least two health aspects was chosen to ensure that health was seen as a complex, multi-dimensional construct [24, 25]. Sampling for at least three days was selected to gain a comprehensive view on an individual's daily life, increase generalizability in terms of days, and observe variability of response [26]. The third criterion (promote health) got defined broadly as the main focus lay on the composition of the self-monitoring within an intervention, while the intervention outcomes and the effectiveness were secondary. The age cut-off was made to focus this review on middle-aged and older adults, as technologies such as smartphones are already more prevalent in individuals younger than 45 years [27] and health app use has been reported in younger ages [28]. Studies before 2007 were excluded, as 2007 can be considered to be a turning point in technological development: the mobile phone with smart functions was introduced to the market [29]. Finally, only studies written in English were included.

Data extraction

Data extraction was inspired by the PRISMA guideline[30]. Information relating to the general study characteristics was extracted, including the country of data collection, sample size, presence/absence of a control group, and population characteristics (age, gender, health status/diagnosis).

With respect to the primary review focus (composition of self-monitoring), data extraction included the type of technology used for the self-monitoring, information on the (theoretical) approaches the intervention was based on, biological/physical, psychological/ emotional, and social aspects of health monitored, details on how often per day monitoring took place (intensity), and for how many days/weeks/months the self-monitoring was performed (duration). Additionally, if, how, and what kind of feedback was given to the participants was deemed of relevance.

The information extracted for the secondary review focus was on the use of/ adherence to the self-monitoring, overall effectiveness of the intervention (positive/negative/no effect on chosen outcome measures), the length of the follow-up period, sustainability of the effects (follow-ups), and the topic of ‘prevention’.

Data synthesis

Due to the heterogeneity of the interventions (population, aim, design, duration, outcome measures, follow-up), a meta-analysis was statistically not appropriate and could thus not be performed. Therefore, a narrative synthesis was conducted. This textual approach summarizes and explains the findings of the synthesis of included studies within a systematic review [31, 32].

Results

Reviewing process

A total of 6425 references were identified through the search strategy. After de-duplication, 3711 hits remained for the abstract screening. 227 articles were included in the full-text screening for eligibility and 20 manuscripts met the inclusion criteria. Reasons for exclusion during the full-text assessment (*n*=207) can be seen in Figure 1. Six additional references were identified via cross-referencing. In total, *n*=26 studies with 21 unique interventions (see Table 1 in Supplemental Material) were included (see Reference list of included studies).

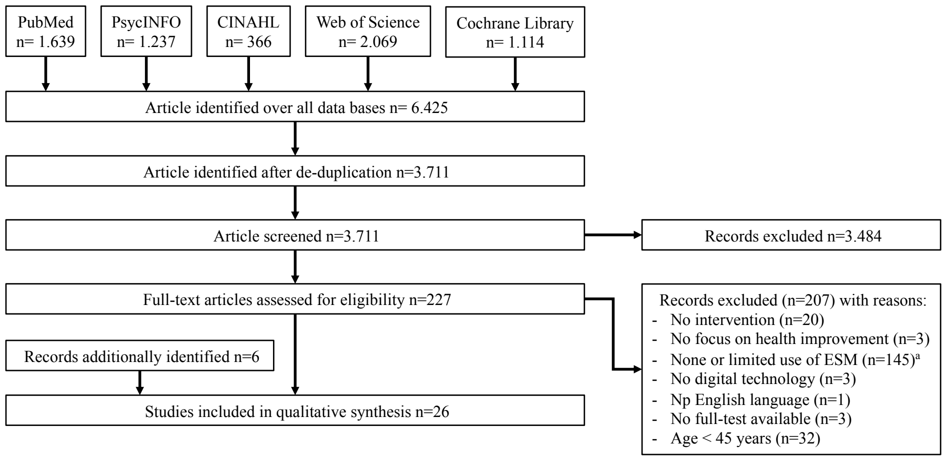


Figure 1. Flow-chart of the review process from data extraction to qualitative synthesis
Note: [a] 'None or limited use of ESM': ESM as outcome only (n=21), <2 aspects of health monitored (n=105), ESM on less than 3 consecutive days (n=19)

General study characteristics

Country of data collection. In total, 13 of the studies took place in the United States[1, 2, 4, 8/12, 9, 11, 13, 14, 18, 19, 20, 21/22, 24]. Three studies were conducted in the Netherlands[5, 10/15, 25/26], two in Norway [7, 16/17] and one each in Germany[23], Austria[3], and New Zealand[6].

Sample size and control groups. The average sample size was 94 ranging from ten [7] to 305 participants[20]. 66% of the studies included at least one control group, while 33% were single-armed [3, 6, 7, 8/12, 9, 19, 23].

Population characteristics. The participants' average age (including participants in control groups) across all studies was 51 years, with a maximum age of 89 years[3]. Only two studies had an average age above 65 years of age [23, 25/26]. The study populations show great variability being comprised of people with a substance use disorder[1, 2, 11, 13, 19], schizophrenia/

schizoaffective disorders[9], and major depression disorder[10/15]. Studies focused furthermore on mixed outpatients[5], coronary heart disease[3], overweight women[6], underactive adults[14], smoking[8/12, 21/22], people with HIV[1, 2, 11, 24], and chronic pain[16/17, 18, 20]. Other studies targeted caregivers of people with dementia[25/26], and 'healthy' individuals[4, 23].

Intervention approaches and elements. All interventions were multi-modal, meaning additional features to the self-monitoring were included. The intervention design consisted of motivational interviewing[1, 2, 11], explicit goal-setting[3, 4, 14, 23], education/ skills training[3, 6, 7, 18, 19, 20], group sessions[7, 8], elements from acceptance and commitment therapy (ACT)[5, 6, 16/17], and elements from cognitive behavioural therapy (CBT)[9, 16/17, 18, 19, 20]. Furthermore, studies highlighted regular clinical care or access to a counsellor [3, 4, 7, 8/12], mindfulness training[16/17, 21/22], physical exercise[7], or disease specific approaches (alcohol intervention based on FRAMES[13], pharmacotherapy[8/10]). One intervention aimed at self-regulatory strategies (i.e. goal setting) derived from the social cognition perspective [14], while two other focused on positive affect (PA) as part of the coping process[10/15, 25/26]. One study offered access to a social network via a web-page[20], and one self-management intervention limited the design to self-monitoring in combination with visualized progress tracking[24]. For the full overview of the Intervention elements, see the Supplementary Appendix B.

Primary review focus: ESM/EMA self-monitoring composition

Self-monitoring Technology. Most technologies were mobile, meaning that participants could enter information at home as well as out of home as the technology could be carried. Different models of personal digital assistants (PDAs) were used: the Dell Axim X5[4, 14,] and the PsyMate[5, 10/15, 25/26]. A PDA is small mobile device programmed to prompt the participant via a sound signal to complete the digital daily questionnaires. The model of the PDA used in one intervention was not specified[21/22]. Other studies used interactive voice response (IVR), a telephone-based technology that enables the caller to interact with a computer using the telephone keypad as the interface. Three studies did not specify the name for the IVR[13,18,19], while two used an IVR called 'HealthCall'[2, 11]. Studies also used a mobile phone survey[24], short message services (SMS)[9], and SMS with a link to a website survey[16/17] as the technological self-monitoring approach. Finally, smartphone apps were developed, namely HealthCall-S[1], originated from the IVR HealthCall, MyCor[3], Smart-T[8/12], and MyTherapy[23]. As well as the mobile approach, stationary devices were also used for self-monitoring: in one intervention, a small computer was attached to the participants' TV system[7]. Two studies used websites via computers for daily log-ins[6, 20].

Prompted self-monitoring intensity per day. The intensity of daily self-monitoring ranged from one to ten self-monitoring moments per day. The intensity of the self-monitoring was categorized as 'low' with one or two self-monitoring assessments per day, as 'medium' with three to five self-monitoring assessments per day, and as 'high' with more than five assessments per day.

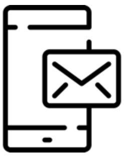
In total, eleven studies used a low monitoring intensity[1, 2, 3, 4, 7, 11, 13, 14, 18, 19, 20]: In four studies, participants were asked in the beginning of the day to reflect on the previous day[1, 2, 11, 13]. Self-monitoring ones daily on the same day took place in six studies[3, 7, 18, 19, 20]. Two other studies prompted the participants twice daily[4, 14]. Medium intensity was described in six studies: One study had three self-monitoring assessments[16/17], while another study prompted the participants three times and asked to additionally provide information after every food intake[6]. Up to four prompts were sent to the participants by one intervention[21/22]. One study included five daily self-monitoring moments at three days per week[8/12]. Finally, participants answered questions on drug use, sexual behavior, and medication adherence ones per day, plus questions on physical and mental health aspects, and context four times a day[23]. High intensity with ten self-monitoring moments was described by three studies[5, 10/15, 25/26]. All studies with high intensity limited self-monitoring to three days per week. One study did not further specify 'daily'[23].

Duration. The duration of the self-monitoring ranged from two weeks[21/22] to six months (approximately 26 weeks)[13]. While most studies asked the participants to self-monitor every day during the intervention period, one intervention limited the assessments to six days per week[9], and four other studies focused on three days per week[5, 8/12, 10/15, 25/26]. For details on the duration see Table 1.

Health aspects: Physical. The Supplementary Appendix C provides an overview of the health aspects that were self-monitored in the interventions All interventions included at least one physical/ behavioural/ biological health aspects. Participants reported on their location[4, 5, 7, 14, 25/26], 'activity'[5, 10/15, 20, 25/26], and quality of sleep[5, 25/26]. Additionally, drug/ substance use[1, 2, 3, 8/12, 11, 13, 19, 24], smoking urge/ cigarette availability[8/12, 24], medication adherence/ use[9, 11, 18, 23, 24], HIV-medication adherence[2] or HIV-related health behaviour[1] was monitored. The self-monitoring also focused on food and/ or water consumption[4, 7, 23], the eating experience (i.e. hunger, fullness)[6], barriers/ enabling conditions for healthy food choices[4], and physical activity and well-being[10/15, 11, 14, 23, 24, 25/26]. Participants reported on COPD symptoms[7], pain[16/17, 18, 20], as well as attention bias/ cognition[21/22]. Finally, self-monitoring included unspecified 'more general questions related to health'[13], behavioural factors[14], coping[18], and events[10/15, 25/26].

Health aspects: Emotional. All interventions included some form of emotional/ psychological or mental health aspect. Self-monitoring questions asked about participants' mood[1, 4, 11, 13, 18, 19, 20], (positive/ negative) affect[5, 8/12, 10/15, 25/26], experienced stress[1, 2, 8/12, 18, 24], wellness/ subjective well-being[1, 2, 3, 11], depression[16/17, 21/22], feelings and thoughts related to avoidance and catastrophizing[16/17], as well as quality of life[2, 24]. Furthermore, participants reflected on their level of mindfulness[6, 21/22], cognition[5], quality/ appraisal of the day[5, 7, 25/26], smoking urge and motivation for cessation [8/12, 19], and coping strategies [9, 18]. Finally, reasons/ motivation for drinking or abstinence[11, 13], motivational factors[14], recreational activities ('time for yourself')[23], self-esteem, and sense of competence[25/26] were part of the self-monitoring.

Table 1. Self-monitoring in the interventions: technologies, intensity, and duration.

	Study ID	Technology	Intensity	Duration (weeks)
IVR 	Aharonovich (2)	IVR (HealthCall)	LOW: Once/day [a]	8.5
	Hasin (11)	IVR (HealthCall)	LOW: Once/day [a]	8.5
	Helzer (13)	IVR	LOW: Once/day [a]	26
	Naylor (18)	IVR	LOW: Once/day	17
	Rose (19)	IVR	LOW: Once/day	12.8
PDA 	Atienza (4)	PDA (Dell Axim X5)	LOW: Twice/day	8
	Batink (5)	PDA (PsyMate)	HIGH: 10 times/day	4 *(3/w)*
	Hartmann (10); Kramer (15)	PDA (PsyMate)	HIGH: 10 times/day	6 *(3/w)*
	King (14)	PDA (Dell Axim X5)	LOW: Twice/day	8
	Van Knippenberg (25/26)	PDA (PsyMate)	HIGH: 10 times	6 *(3/w)*
	Ruscio (21/22)	PDA	MEDIUM: Up to 4 times/day	2
SMS via Smartphone/ Mobile phone 	Granholm (9)	SMS	MEDIUM: 3 times/ day	12 *(6/w)*
	Kristjánsdóttir (16/17)	SMS with link to website	MEDIUM: 3 times/ day	4
	Swendeman (24)	Mobile phone survey	MEDIUM: Some once/day; some 4 times/day; + self-initiated	6
Smartphone app 	Aharonovich (1)	Smartphone app (Healthcall-S)	LOW: Once/day [a]	8.5
	Ammenwerth (3)	Smartphone app (MyCor)	LOW: Once/day	16
	Businelle (8); Hébert (12)	Smartphone app (Smart-T)	MEDIUM: 5 times/ day	3 *(3/w)*
	Steinert (23)	Smartphone app (MyTherapy)	LOW: Daily (n.o.s.)	4
Computer 	Boucher (6)	Website via computers	MEDIUM: 3 times prompted; every meal/ snack	14
	Burkow (7)	Small computer attached to TV	LOW: Once/day	9
	Ruehlman (20)	Website via computers	LOW: Once/day	6

Note: IVR=interactive voice response; PDA=personal digital assistant; SMS=short message services; (…/w)=number of self-monitoring days per week; [a] asked to reflect in the morning on previous day.

Health aspects: Social. N=8 interventions included social aspects, meaning participants provided information if they were alone or with others. The questions focused on sexual interactions and protection[1, 24], social company[5, 10/15, 25/26], socialization[9], or relationships with the partners[13]. Recreational activities reflecting on cultivating social contacts were also included[23]. Thirteen studies did not ask about any social aspects in everyday life (note: some elements might also refer to the other health categories).

Feedback. The information collected during the self-monitoring was in nearly all studies feedbacked (*n*=23) to the participants. Only three study designs did not include any form of feedback[5, 6, 21/22]. The feedback was either produced by a healthcare professional or through a preprogramed technological device/service. Feedback from the healthcare professionals were delivered in face-to-face sessions, online consultations, via e-mail or through voice recorded messages. The technology either send automated messages or could provide visual feedback on demand. In one intervention, healthcare profession provided daily written feedback [16/17]. In most studies, however, healthcare professionals gave feedback on a weekly, bi-monthly, or monthly level. The programmed feedback was available in most studies every day and in two interventions weekly. Table 2 provides details on the characteristics of the feedback.

Table 2. Characteristics of feedback.

Feedback produced by	Form of presentation	Frequency	Study ID
Healthcare professional	Face-to-face	Weekly	10/15
		Every two weeks	25/26
		Twice (at day 30 and day 60)	1, 2, 11
	Online consultation	Weekly	7
	Message from therapist	Daily	16/17
		Monthly	13
	Recorded personal message (IVR)	Monthly	18. 19
Programmed Technology	Automated messages	Daily	4
		Weekly	3, 14
		Tailored to status	8/12
		Interactive	9
	Self-initiated	On demand	20, 23, 24

Note: IVR= interactive voice response

The content of the feedback depended on the self-monitoring items. Therefore, the feedback included drinking behaviour or drug use[1, 2, 11, 13], smoking behaviour[8/12], or information related to the individually set goals (e.g. steps)[3, 7, 14, 23]. Furthermore, part of the feedback was dietary intake[4], medication adherence, socialization or auditory hallucinations[9], or positive affect in daily contexts[10/15, 25/26]. Interventions included also feedback on general diary content[16/17], coping skills, stress, and pain level[18, 19], or mood/ activity boosters and pain soothers[20].

Secondary review focus: usability, effectiveness, sustainability, and prevention

Usability/ Compliance/ Adherence. The terminology varied between studies when reporting on the participants' engagement in self-monitoring including 'adherence', 'use', 'compliance' or 'engaged'. The lowest average adherence rates were 51% (PDA Dell Axim 5)[4] and 56% (IVR)[19] (low self-monitoring intensity). The highest median use rates were 86/87% (Smart-T; text messages)[8/12, 9] (medium self-monitoring intensity) and 95% (HealthCall-S smartphone app)[1] (low self-monitoring intensity). Most studies reported an adherence rate between 64% and 76%[2, 5, 10/15, 11, 14, 16/17, 21/22, 25/26]. In three studies, no information on the adherence was provided[18, 20, 23]. Finally, one study reported the adherence to self-monitoring without a percentage as 'most entered data on a daily basis' (page 7) [7]. A number of studies noticed a decrease of adherence and use over the course of the intervention[3, 4, 6, 13, 19, 24]. One study described furthermore that the web-based visualization focused on survey responses over time were difficult to use and interpret, and therefore rarely used by the participants[24]. One intervention was evaluated in an RCT as well as a process evaluation[25/26]. No other interventions provided process evaluations.

Effectiveness. Details of the effectiveness can be found in the Supplementary Table 1. 96% of all studies reported health improvements at least on one outcome measure right after the intervention or at follow-up. One study failed to find significant effects on the outcome measures, however, participants reported that the ACT exercise (available on demand in distressing situation to deal with feelings and thoughts in an ACT-consistent manner) and metaphors (illustrated metaphors serving as reminders/cues to reactive previously learned ACT concepts) were useful components[5]. Next to the significant health improvements, *n*=11 studies reported that some outcome measures did not show a significant change post-intervention [1, 3, 5, 6, 9, 10/15, 11, 12, 22, 23, 26]. One study found a negative intervention effect with higher alcohol consumption in the self-monitoring IVR group, potentially explained through a confounder effect[13]. The same study highlighted a therapeutic advantage of the feedback compared to self-monitoring only. Findings regarding the added benefit of a feedback on top of the self-monitoring were limited and mixed: studies reported non-significant group differences[10, 25/26], or significant effects of the self-monitoring plus feedback compared to self-monitoring only[15]. Results furthermore stressed the relevance of tailored messages (i.e. with respect to triggers)[12], the advantage of daily self-monitoring compared to bi-weekly to increase awareness and behavioural change[24], and the importance of a personal coach providing face-to-face feedback to stimulate and implement new insights into daily lives[25].

Follow-up and sustainability. Twelve studies did not include or report on follow-up assessments after the main intervention period and therefore no information on the sustainability of the intervention effects was available. Sustained effects were found on at least one outcome measure after two months[26], three months[6]/ twelve weeks[8], 14 weeks[20], five months[16], six months[15], eight months[18], and twelve months[2]. In two studies, within-group differences remained, while group-differences disappeared at 11/12-month follow-up[11, 17].

Prevention. A small number of studies included the idea of disease prevention in their intervention. Relapse prevention was part of the six-week inpatient treatment (ACT group therapy) prior to the self-monitoring period (ACT in daily life)[5], as well as the IVR based interventions for chronic pain[18] and alcohol use disorder[19]. Additionally, authors concluded that the intervention prevented increases in functional impairment and symptom levels in women with chronic widespread pain following inpatient rehabilitation[16]. The "Mind, Body, Food" program functioned as a weight gain prevention[6]. Finally, monitoring functioning in caregivers of people with dementia might potentially prevent higher levels of burden in a later stage[26].

Discussion

The primary aim of this review was to describe the composition of self-monitoring interventions for middle-aged and older adults aiming to improve health. The reviewed literature resulted in the identification of 26 studies with 21 unique interventions using active ESM/EMA self-monitoring. The strength of this review lies in the inclusion of all active self-monitoring interventions using technology to describe the diversity of intervention designs and thus stimulate new approaches. The chosen definition of self-monitoring aimed to represent the intersection between both ESM and EMA, while the inclusion criteria ensured that health was considered a multi-dimensional construct.

With regards to the general characteristics of the included studies, the interventions focused on a wide range of physical and psychological health issues and were conducted in high-income countries. Studies focused mainly on middle-aged adults as only two studies had an average age above 65 years of age[23, 25/26]. One of these studies provided insufficient information on the design of the four-week program and participant's use of the 'MyTherapy' smartphone app (intensity of sampling and compliance unclear)[23], which highlights the need for consistent reporting as also suggested by an EMA review in youth [33]. The other study including older adults[26] used the PDA 'PsyMate' over six weeks with a high sampling intensity (i.e. 10 times/day) and reported a high compliance rate (78%). This compliance rate is similar to the rate reported in youth (76%) [34]. Even though younger individuals might be particular amendable to monitor health aspects using technology such as smartphone apps, the willingness seems not to differ across ages, suggesting age itself to not be a barrier per se [35]. Nevertheless, more research in older adults is needed to determine potential variations from the findings of this review reflecting digital self-monitoring in middle-aged adults.

Digital self-monitoring was also just one element within the multi-modal set-ups. This multi-modality in combination with the diverse study designs (i.e. 2/3 included a control group) limits the expressiveness with respect to the direct effectiveness of digital self-monitoring on health, which was in this review secondary. When reviewing complex interventions, it is recommended to focus on the aspects of complexity that are depict the main research question [36]. In the present review, this focus was on the composition of digital self-monitoring within interventions. The following elements of digital self-monitoring stood out through the narrative synthesis and should be considered in future set-ups:

Mobile technology

In everyday life, most individuals spend time not only at home, but a variety of places such as at work, public places, or nature. To promote digital self-monitoring in all environments, a mobile technology is essential. Three studies, however, used a stationary device (i.e. computer or computer in combination with TV system)[6, 7, 20], which limits the flexibility of the digital self-monitoring in everyday life resulting in an incomplete view of one's daily functioning. The non-mobile approach could furthermore explain the low self-monitoring adherence in one of the studies: only 10% of the participants used the Eating Awareness Tracker within the 'Mind, Body, Food' intervention for at least 12 out of 14 weeks[6].

The studies that used a portable technology chose PDAs, smartphone apps, or mobile phones (surveys, SMS/ with link to website). The benefit of smartphone apps for the self-monitoring lies in the fact that users can install apps on his/her own smartphone, which is comfortable as no new device needs to be learned and carried. Additionally, people (users or researchers) do not need to purchase a whole new technology. As individuals spent multiple hours a day on their smartphones [37], the task to repeatedly self-monitor momentary aspects for a couple of minutes seems unproblematic. Contrary, giving the participant a new technological device such as a PDA might increase the excitement and thus adherence. In this review with regard to the adherence, there was no trend identified for one mobile device being superior to another mobile device.

Next to smartphone (apps), IVRs were used through which individuals interacted with a computer by calling it and responding to questions via the keypad of the telephone. All IVR studies instructed the participants to use the IVR once per day and to reflect on the previous day. On one hand, this retrospective approach compared to traditional ESM 'in-the-moment' reflections might introduce a slight memory-bias, which could affect the ecological validity [38]. On the other hand, the IVR interventions had durations of more than 8 weeks[2, 11, 18, 19], which was twice as long as some of the non-IVR interventions[5, 8, 16/17, 21/22, 23]. The longest study period described in this review of 6 months also used IVR[13]. This long self-monitoring duration using IVR, however, was also paired with a described reduction of engagement with the self-monitoring in two studies[13, 19] .

Surprisingly, no intervention included wearables or other technological devices to combine active self-monitoring with passive self-monitoring of additional physical information. Recent research reveals that wearables are not only easy to use for older adults, but can also improve aspects of health by, for example, encouraging participants to increase their daily level of physical activity [39, 40]. The dichotomy of active and passive self-monitoring used in the present review might furthermore not be applicable to all technologies, as approaches can be combined [41] and passively collected data could also lead to awareness for behaviours via feedback and thus health benefits [42].

Generally, the choice for one or the other mobile technology seems to be partially influenced by the workplace as the IVR studies, for example, were all conducted or in collaboration with the University of Vermont and Colombia University, while the PDA PsyMate studies origin from Maastricht University. The findings of this review could facilitate researchers and clinicians to expand their horizon and adopt other technological solutions into their institute. This adaptation of new approaches may result in new insights and additional advantages for the target populations. Another issue might lie in the tendency of inventing similar devices/

services instead of building on existing knowledge. General guidelines can contribute to less time spent on testing the basics of the technology and more time channelled into designing the modalities that actually improve health and change behaviours.

Duration, intensity, and reduced engagement

Currently, no guideline for the duration or intensity of digital self-monitoring within interventions exists. Within the studies included in this review, the duration and intensity of the digital self-monitoring varied strongly and no clear trend could be identified. The diversity might be related to the unavailability of guidelines, the variety of health issues targeted by the interventions, and the fact that the health improvements might take unequally long to be reached. A delayed health improvement could be seen, for example, in the study of Van Knippenberg et al. (2018) as some significant changes did not appeared after the intervention, but at two-months follow-up [43].

When reflecting on the sampling intensity, one benefit of a high sampling intensity (i.e. 10 times/day) is the possibility to identify pattern and fluctuations over the day [44]. Furthermore, the person may be desensitize to the procedure and therefore reduced reactivity to the self-monitoring method through a higher sampling load [11]. Contrarily, a high sampling intensity can be time-consuming and burdensome for the individual in the long-term. In the included studies, there was no visible relation between a high intensity resulting in low adherence. The intensity as well as duration might prospectively be chosen with respect to the individual's preferences. Furthermore, a re-evaluation of the set-up after some weeks or months might be useful, as the health improvement could be reached earlier or later than expected. Flexible adjustment of the intervention in combination with a person-cantered approach [45] could thus improve optimal functionality.

A number of studies noticed a decrease of adherence over the course of the self-monitoring intervention[3, 6, 13, 19, 24]. This decline in engagement has been noted by other eHealth studies [46-50]. In an EMA review focused on youth, recommendations include offering incentives or integrating measurement bursts (self-monitoring for several days or weeks followed by a break and then continuing) to maintain interest [34]. Future research needs to investigate ideas on reward systems or gamifications [51] to motivate sustained engagement resulting potentially in lasting behavioural change. Theoretically, behavioural change maintenance is complex and includes factors related to the individual motive, self-regulation, psychological and physical resources, habits, and environmental and societal influences [52]. These factors might guide future developments and intervention designs.

Self-monitoring of health aspects: a discrepancy between theory and practice

To improve self-management through self-monitoring, health as a complex and dynamic system requires interventions that take all health aspects into account: physical, psychological, and social. Only eight of the 21 interventions asked the participants to reflect on social factors. Social health refers to the view that an individual can manage and maintain a balance between opportunities and limitations in social and environmental challenges and thus experience well-being despite a health issue [25]. In certain fields, researchers emphasize that more attention needs to be paid to social health to improve participation and well-being [53, 54].

The discrepancy in the reviewed self-monitoring interventions between the theoretical importance of social aspects of health [24] and in practice this aspect being widely neglecting might indicate that the digital self-monitoring interventions need adjustments to optimally support health. In case the interventions included self-monitoring of social aspects, the social information was used in different ways. Two interventions focused one face-to-face feedback session on social interactions and related positive affect[10/15, 26]. This approach could raise awareness for the social network available and the importance to maintain it[25]. Self-monitoring of sexual behaviour also increased awareness of the relationship between this behaviour and substance use and other triggers[24]. Furthermore, socialization and recreational activities (i.e. cultivate social contact) were main goals that participants could choose to improve[9,23]. The other studies did not include details on how the self-monitored information on social aspects (i.e. sexual interactions and protection, relationship to partner) was used[1, 13]. Conclusively, the evidence on how social aspects can utilized in self-monitoring interventions is limited and future research is urged to investigate further. Nevertheless, the theoretical importance of interpersonal health aspects is not translated well into practice.

Feedback: health professional vs. programmed technology

All studies provided some form of feedback, except three[5, 6, 21/22]. While one of them [55] did not find a significant change in the self-report outcome measures (i.e. psychological flexibility, symptoms, coping, or quality of life), the results of Boucher et al. (2016) showed significant within-group improvement in intuitive eating, psychological flexibility, and general mental health as well as decrease in binge eating [56]. In this study, however, the success might be more influenced through other intervention elements (teaching ACT-based skills) rather than feedback of self-monitoring information as only 10% of the participants engaged in the whole 14-week self-monitoring[6].

All other interventions reported some of the self-monitoring information back to the individuals. Generally, a trade-off between the frequency and amount of involvement of the healthcare professional could be observed: while automated feedbacks would be used more often, they might also be less personal. The involvement of health professionals such as coaches or psychologists was described as pleasant and useful as described in the process evaluation of one intervention[25] and the qualitative results stated in Burkow et al. (2015) [57]. Due to limited resources, however, involvement might not be feasible on a daily level.

Providing feedback can be more challenging than one might think as the question remains if the person can cognitively grasp the information and translate it into a behavioural change [58]. Generally, feedback is recommended to be timely and tailored [59]. Prospectively in self-monitoring intervention, a combination of both programmed feedback/ progress tracking and a weekly or monthly personal conversation might provide the individual with the ideal support. This combined approach is in line with the 'blended care principle', which highlights the use of both online modules and session with a personal coach to support self-management [60]. The personal contact could be provided through written messages[16/17], online consultations[7], face-to-face sessions[1, 2,10/15, 11, 25/26], or even recorded voice messages[18, 19] as illustrated by the reviewed studies.

Intervention effects, their sustainability, and mechanisms

This systematic review is not intended to fully evaluate the effectiveness and sustainability of effects. Rather, the narrative synthesis provides descriptive conclusions that should not be generalized: almost all intervention reported a significant positive effect on health either by comparing intra- or inter-group differences. As expected, the specific results were diverse. Highlights include improved mood[10, 21, 26], better health-related quality of life[7], healthier eating habits and/or physical activity[3, 4, 6, 14], decreased levels of pain[18, 20], as well as increased medication adherence[9, 23].

One study did not result in significant improvements in the chosen outcome measures (i.e. psychological flexibility, symptoms, avoidant coping)[5]. The primary aim of this project was to assess the feasibility and acceptability of a fully automated mobile ACT intervention in daily life delivered by a PDA (i.e. PsyMate). The participants showed great enthusiasm for participation resulting in twice as many participants as aimed for. Furthermore, the completion rate was high (76%) and the high sampling intensity (10 times/day) did not seem to have interfered. The non-significant results might be explained by the short follow-up period as differences could be visible at a later time point. Additionally, a ceiling effect could have influenced the scores as an intensive inpatient treatment had occurred prior to the intervention[5].

Another study led to negative health outcomes, namely an 'increase' in alcohol consumption measured with a retrospective instrument. This outcome might be explained through a measurement confounder[13]. The authors argue that this finding is counterintuitive and a large body of literature supports the beneficial influence of self-monitoring and feedback on alcohol use. The given explanation refers to the observation that individuals commonly underestimate their consumption on the retrospective instrument, but through the self-monitoring their report increased in accuracy, which then resulted in a misleading result. Through another analysis, independent of this confounder, self-monitoring in particular in combination with feedback seems to be beneficial to reduce alcohol consumption[13].

The evaluation of the sustainability of intervention effects was not included in the majority of studies. When follow-ups were included, the periods ranged from two[25/26] to twelve months[2, 11]. Some studies faced thus the fading of significant intervention effects after some weeks or months[11, 17]. Achieving as well as maintaining a behavioural change to improve health is complex and influenced by various internal and external factors. Additional interventions features after the main period might, therefore, be necessary to assess the health status and potentially boost it. Overall, more research is needed as the question how sustainable effects of self-monitoring interventions are with respect to maintained health improvements is understudied. On the level of public health care systems, not only long-term financial solutions are needed, but also the joined development, provision, and monitoring of eHealth approaches including all stakeholders (private sector, beneficiaries, final users) plays an important role in the sustainability [61].

When trying to explain underlying mechanisms, the Transtheoretical Model of Health Behaviour Change claims that individuals go through six 'stages' during the process of change namely precontemplation, contemplation, preparation, action, maintenance, and termination [62]. Interventions are therefore suggested to be stage-matching and individualized [63]. Next to self-monitoring, a systematic review linked the following techniques to particularly successful interventions: provision of instructions, relapse prevention, and prompting practice [64]. Furthermore, the behaviour centred design approach urges to create surprise, revalue behaviour, and disrupt performance to enable a behavioural change [65]. While digital self-monitoring could support this process, the theoretical background might require further investigation. Overall, there are more than 80 theories on behaviour and behavioural change [66]. Future research might elaborate on the theoretical basis to support the practical recommendations for self-monitoring interventions provided in this review.

Prevention: possibilities and challenges

The idea to use digital self-monitoring to not only treat already existing health issues, but also prevent problems before they manifest, may (theoretically) sound promising: a person self-monitors him/herself, increases awareness for the own lifestyle, and individuals feel motivated to become or stay healthy. Unfortunately, the mechanisms of disease prevention are more complex.

One difficulty relates to the question how engagement in self-monitoring can be promoted over months and even years to achieve long-lasting health results. Taken the example that a healthier lifestyle can reduce the risk for strokes or dementia [67, 68], an individual would need to change and maintain this lifestyle for decades. Innovative solutions with long-term research designs are required to study this process and to gain insight into the motivational aspects. This question aligns with the aspect of sustainability described above. For how long is self-monitoring needed to reach 'the healthy lifestyle'? How can this lifestyle be maintained? As relatively little faction of health spending gets channelled into preventive compared to curative strategies [69], the development and implementation of digital prevention strategies is challenging and in its infancy.

Limitations and future directions

First, the degree of bias within this review by only including studies published in English and the likely publication bias associated with including only published manuscripts is acknowledged. Second, as the review's focus was on the composition of digital self-monitoring, studies were not included based on the quality of effectiveness. However, the included articles were sources from peer-reviewers journals, signifying that all of them had an academic level and quality. Third, by limiting the time period (2008 to April 2018), this review does not aim to be exhaustive but presents an initial picture of digital self-monitoring interventions. Applying the search strategy once more in September 2019 resulted in 1167 hits for the years 2018-2019 indicating an exponential development. A quick review of the PubMed hits (n=165) using the same search strategy (Appendix A) resulted in identifying one additional study: In this RCT [70], participants (n=171, mean age= 50,6 yrs.) became more physically active by using a website to monitor affect, experienced exertion, and steps (pedometer). The website provided the participants with tips and peer support, but no information on the mobile access of the website was provided. Furthermore, the intervention effects had largely disappeared after twelve-months, which is in line with the presented results (section 4.5). No elements of this intervention seem to greatly diverge from the findings of this review. The updated search revealed many protocols, therefore we believe that an updated review in a couple of years could be beneficial for the field. With regards to the methodological issues, self-monitoring was defined and operationalized generally orientated on momentary assessments such as ESM and EMA and aiming to find the intersection, but this definition might diverge from other perspectives on ESM/EMA. Finally, even if different populations were included in this review, the results cannot be generalized to other age groups or ethnicities.

In the future, digital self-monitoring interventions as a promising eHealth solution may be used to support people not only in rural areas, but also middle- and low-income countries [71, 72]. Additionally, active self-monitoring could be linked with automatic self-monitoring such as wearables [73] to evolve the solid status of the current self-monitoring technology further. Even though health professional's acceptance of eHealth interventions and aftercare needs to improve before fully implementing eHealth into practice, which is seen as a complex process [4, 74], digital phenotyping [75], when used in a responsible and ethical way, may have great advantages in health promotion.

Conclusion

Overall, digital self-monitoring technologies seem to be suitable to understand and support health-related self-management and hold promise for future trials. The composition of digital self-monitoring interventions in middle-aged and older adults showed a great diversity, particularly with respect to the duration, sampling intensity, and multi-component design. Nevertheless, several elements stood out and should be considered in future digital self-monitoring interventions: (i) Mobile technology can ensure flexible use in everyday life. (ii) Feedback both automatically and in person may support the individual throughout the intervention. (iii) Social health aspects are partially neglected and need more attention. Research may prospectively investigate the sustainability of intervention effects, ways to promote long-term engagement, possibilities for disease prevention, the most suitable theoretical model for digital self-monitoring, and include more older adults >65 years of age.

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Supplementary Materials:

References of included studies
Appendix A. Search Strategy
Appendix B. Study Characteristics
Appendix C. Health aspects monitored

References of Included Studies

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Appendix A. Search strategy.

1 *Experience Sampling/ Ecological Momentary Assessment*

PubMed:

"experience sampling"[tiab] OR "ecological momentary assessment"[tiab] OR "event-contingent recording"[tiab] OR "ambulatory assessment"[tiab] OR "intensive longitudinal assessment"[tiab] OR "real-time data capture"[tiab] OR "event-sampling"[tiab] OR "time sampling"[tiab] OR "self-recording"[tiab] OR "self-monitoring"[tiab] OR "diary"[tiab] OR "diaries"[tiab] OR "ecological momentary assessment"[MeSH Term]

PsycInfo and CINAHL:

"experience sampling" OR "ecological momentary assessment" OR "event-contingent recording" OR "ambulatory assessment" OR "intensive longitudinal assessment" OR "real-time data capture" OR "event-sampling" OR "time sampling"OR "self-recording" OR "self-monitoring" OR "diary" OR "diaries"

Web of Science and Cochrane Library:

"experience sampling" OR "ecological momentary assessment" OR "event-contingent recording" OR "ambulatory assessment" OR "intensive longitudinal assessment" OR "real-time data capture" OR "event-sampling" OR "time sampling"OR "self-recording" OR "self-monitoring" OR diary OR diaries

2 *Intervention*

PubMed:

"intervention*"[tiab] OR "therapy"[tiab] OR "therapeutic*"[tiab] OR "treat*"[tiab] OR "rehabilitation"[tiab] OR "program*"[tiab] OR "prevent*"[tiab] OR "primary prevention"[tiab] OR "secondary prevention"[tiab] OR "tertiary prevention"[tiab] OR "health promotion"[tiab] OR "health education"[tiab] OR "support"[tiab] OR "advice"[tiab] OR "counseling"[tiab] OR "counselling"[tiab] OR "training"[tiab] OR "coaching"[tiab] OR "motivational interview"[tiab] OR "motivational interviews"[tiab] OR "motivational interviewing"[tiab] OR "therapy [Subheading]" [MeSH Term] OR "therapeutics" [MeSH Term] OR "therapy, computer-assisted" [MeSH Term] OR "rehabilitation" [MeSH Term] OR "primary prevention" [MeSH Term] OR "secondary prevention" [MeSH Term] OR "health promotion" [MeSH Term] OR "health education" [MeSH Term] OR "behavior control" [MeSH Term]

PsycInfo and CINAHL:

"intervention*" OR "therapy" OR "therapeutic*" OR "treat*"OR "rehabilitation" OR "program*" OR "prevent*" OR "primary prevention" OR "secondary prevention"OR "tertiary prevention" OR "health promotion" OR "health education" OR "support" OR "advice"OR "counseling" OR "counselling" OR "training" OR "coaching" OR "motivational interview*" OR DE "intervention" OR DE "treatment" OR DE "rehabilitation" OR "prevention" OR DE "health promotion" OR DE "health education" OR DE "counseling" OR DE "training" OR DE "coaching" OR DE "motivational interviewing"

Web of Science and Cochrane Library:

intervention OR interventions OR therapy OR therapies OR therapeutic OR therapeutical OR treat OR treatment OR treatments OR rehabilitation OR rehabilitations OR rehabilitate OR program OR programs OR prevent OR preventive OR prevention OR preventions OR "primary prevention" OR "secondary prevention"OR "tertiary prevention" OR "health promotion" OR "health education" OR support OR supporting OR advice OR advicing OR counsel OR counseling OR counselling OR training OR train OR trainings OR coaching OR coachings OR "motivational interview"

3 *Mobile Technology*

PubMed:

“technology”[tiab] OR “wireless technology”[tiab] OR “smartphone*”[tiab] OR “phone*”[tiab] OR “computers, handheld”[tiab] OR “tablet*”[tiab] OR “iPad”[tiab] OR “mobile device”[tiab] OR “mobile devices”[tiab] OR “portable device”[tiab] OR“portable devices”[tiab] OR “application*”[tiab] OR “app”[tiab] OR “apps”[tiab] OR “digital”[tiab] OR “online”[tiab] OR “wireless technology”[MeSH Term] OR “smartphone”[MeSH Term] OR “phone”[MeSH Term] OR “computers, handheld”[MeSH Term] OR “mobile application”[MeSH Term]

PsycInfo and CINAHL:

“technology” OR “wireless technology” OR “smartphone*” OR “phone*”OR “computers, handheld” OR “tablet*” OR “iPad” OR “mobile device*”OR “portable device*”OR “application*”OR “app”OR “apps” OR “digital” OR “online” OR DE “technology” OR DE “electronic communication” OR DE “mobile devices” OR “online therapy” OR DE “computer application” OR DE “Computer assisted therapy” OR DE “online therapy”

Web of Science and Cochrane Library:

technology OR technologies OR “wireless technology” OR smartphone OR smartphones OR phone OR phones OR “computers, handheld” OR tablet OR tablets OR iPad OR iPads OR “mobile device” OR “mobile devices” OR “portable device” OR “portable devices” OR application OR applications OR app OR apps OR digital OR online

4 *Promoting health*

PubMed:

“health”[tiab] OR “mental health”[tiab] OR “well-being”[tiab] OR “wellbeing”[tiab] OR “fitness”[tiab] OR “physical fitness”[tiab] OR “activity of daily living”[tiab] OR “quality of life”[tiab] OR “health behavior”[tiab] OR “health status”[tiab] OR “improve*”[tiab] OR “recovery”[tiab] OR “program evaluation”[tiab] OR “outcome*”[tiab] OR “QoL”[tiab] OR “promote”[tiab] OR “endorse”[tiab] OR “build up”[tiab] OR “boost”[tiab] OR “support”[tiab] OR “health index”[tiab] OR “health indices”[tiab] OR “health profile”[tiab] OR “health profiles”[tiab] OR “assessment*”[tiab] OR “report*”[tiab] OR “function*”[tiab] OR “instrument*”[tiab] OR “measure*”[tiab] OR “questionnaire*”[tiab] OR “scale*”[tiab] OR “score*”[tiab] OR “status”[tiab] OR “survey*”[tiab] OR “patient reported outcome measures”[MeSH Term] OR “treatment outcome”[MeSH Term] OR “health”[MeSH Term] OR “mental health”[MeSH Term] OR “physical fitness”[MeSH Term] OR “activity of daily living”[MeSH Term] OR “quality of life”[MeSH Term] OR “health behavior”[MeSH Term] OR “health status”[MeSH Term] OR “program evaluation”[MeSH Term] OR “Outcome Assessment”[MeSH Term]

PsycInfo and CINAHL:

“health” OR “mental health” OR “well-being” OR “wellbeing” OR “fitness” OR “physical fitness” OR “activity of daily living” OR “quality of life” OR “health behavior” OR “health status” OR “improve*” OR “recovery” OR “program evaluation” OR “outcome*” OR “QoL” OR “promote” OR “endorse” OR “build up”OR “boost” OR “support” OR “health index*” OR “health indices” OR “health profile*” OR “assessment*” OR “report*” OR “function*” OR “instrument*” OR “measure*” OR “questionnaire*” OR “scale*” OR “score*” OR “status” OR “survey*” OR DE “health” OR DE “mental health” OR DE “well being” OR DE “quality of life” OR DE “lifestyle” OR DE “health behavior” OR DE “lifestyle changes” OR DE “recovery (disorders)” OR DE “treatment outcomes” OR DE “measurement” OR DE “ability level” OR DE “questionnaires”

Web of Science and Cochrane Library:
health OR "mental health" OR "well-being" OR wellbeing OR fitness OR "physical fitness" OR "activity of daily living" OR "quality of life" OR "health behavior" OR "health status" OR improve OR improment OR recovery OR "program evaluation" OR outcome OR outcomes OR QoL OR promote OR endorse OR "build up" OR boost OR support OR supporting OR "health index*" OR "health indices" OR "health profile*" OR assessment OR assessments OR report OR function OR functional OR functions OR instrument OR instruments OR measure OR measures OR questionnaire OR questionnaires OR scale OR scales OR score OR scores OR status OR survey OR surveys

#1 AND #2 AND #3 AND #4 AND #5
(applied 17.04.2018)

Further information:
Pubmed, PsycInfo and CINAHL were limited to
Date 2007 – 2018
English language
Human Studies

Web of Science was limited to
Date 2007-2018
English language

Cochraine Library was limited to
Date 2007-2018

Due to database options, the limitations for Web of Science and Cochrane Library were less strict, resulting in a broader search and more hits. Records were then manually scanned for the other criteria (date, language and species).

Appendix B. Study Characteristics.

Study ID, and Population	Study Design (N), and groups	Age, and gender (% female)	Intervention elements (in addition to self-monitoring)
1. Aharonovich et al. (2017a) USA: Adults with HIV using non-injection drugs and binge drinking	RCT (42); Group A: MI-only; Group B: MI+Healthcall-S	Mean=50.96 Range 34-63 16.3%	MI, positive reinforcement, personalized feedback
2. Aharonovich et al. (2017b) USA: Adults with HIV using non-injection drugs	RCT (240); Group A: MI-only; Group B: MI+HC; Group C: educational control	Mean=46.54 23%	MI, personalized feedback
3. Ammenwerth et al. (2015) AT: Patients with coronary heart disease	Two-phased, single-armed study (25)	Mean=63 Range 47-89 4%	Patient education, goal-setting, feedback, regular clinical visits
4. Atienza et al. (2008) USA: Healthy older adults	Randomized trial (36); Group A: PDA to monitor eating habits; Group B: nutritional education material	Mean=60.6 69.5%	Individualized feedback, goal-setting, support
5. Batink et al. (2016) NL: General outpatient volunteers	Observational comparison study (161); Group A: ACT-DL; Group B: participants who did not volunteer	Mean=46.6 Range 22-68 55%	ACT training, add-on ACT-DL
6. Boucher et al. (2016) NZ: Middle-aged overweight woman	Single-armed pilot intervention study (40)	Mean=44.8 100%	ACT-based, skills for intuitive eating taught via videos
7. Burkow et al. (2015) NO: Patients with COPD	A mixed-methods pilot study, single-armed (10)	n=1: 45-54 n=6: 55-64 n=3: 65-73 50%	Group-based education (online), exercise, individual consultations
8. Businelle et al. (2016) USA: Smokers willing to quit smoking	Single-armed study (59)	Mean=52 54%	Standard cessation clinical care (i.e. group counselling, pharmacotherapy), automated messages

Outcomes	Follow-up post-intervention period
POSITIVE EFFECT: both treatment groups reduced drug and alcohol use by end of treatment, with MI + Healthcall-S showing significantly greater reductions than MI-only in QuantU and NumDU. NO EFFECT: reductions in alcohol quantity and frequency in the MI+Healthcall group.	No FU
POSITIVE EFFECT: Across all groups, at end-of-treatment, frequency and quantity of NIDU decreased, with significantly greater reductions in the MI-only group.	12-month FU: indicated sustained benefits of MI + HC and MI-only relative to control.
POSITIVE EFFECT: Patients reported feelings of self-control, and motivation for life-style changes; Pre-defined goals for physical activity were reached in up to 86% and 73% of days, respectively; Quality of life improved from 5.5 at study entry to 6.3 at the end. NO EFFECT: Reductions in blood pressure and heart rate or an improvement in reaching defined goals could not be observed.	No FU
POSITIVE EFFECT: Relative to controls, intervention participants reported significantly greater increases in vegetable servings as well as a trend toward greater intake of dietary fiber from grains.	No FU
POSITIVE EFFECT: Both ACT exercises and metaphors were experienced as useful components of the training NO EFFECT: no significant effects of the ACT-DL on psychological flexibility, symptoms, avoidant coping, or quality of life.	No FU
POSITIVE EFFECT: within-group increases in intuitive eating, psychological flexibility, and general mental health as well as significant decreases in binge eating NO EFFECT: no significant within-group change in BMI from pre-to-postintervention or postintervention to 3-month FU.	3-month FU: maintained effects for intuitive eating, further improvements in binge eating, and general mental health; n.s. tendency of further improvement in psychological flexibility.
POSITIVE EFFECT: probable clinically relevant significant improvement in health-related quality of life.	No FU
POSITIVE EFFECT: A total of 41% (24/59), 17% (10/59), 31% (18/59), 27% (16/59), 22% (13/59), and 20% (12/59) of participants met criteria for point prevalence abstinence at the quit date, week 1, week 2, week 3, week 4, and week 12 follow-up visits, respectively.	12-week FU: 20% of all participants were biochemically confirmed abstinent.

Appendix B. Continued.

Study ID, and Population	Study Design (N), and groups	Age, and gender (% female)	Intervention elements (in addition to self-monitoring)
9. Granholm et al. (2011) USA: Community-dwelling individuals with schizophrenia or schizoaffective disorders	Single-armed intervention study (55)	Mean=48.7 31%	CBT techniques, automated messages
10. Hartman et al. (2015) NL: Pharmacologically treated outpatients with a major depression disorder	RCT; Group A: experimental group (33); Group B: pseudo-experimental group (36); Group C: control group (33)	Mean=48 54.9%	PA-focused feedback
11. Hasin et al. (2013) USA: Adults with HIV who met heavy drinking criteria	Randomized trial of a brief intervention; Group A: MI-only (82); Group B: MI+HealthCall (88); Group C: control (88)	Mean=45.7 22.1%	MI, personalized feedback
12. Hébert et al. (2018) USA: Smokers willing to quit smoking	See 8	See 8	See 8
13. Helzer et al. (2008) USA: Adults who met the heavy drinking criteria and had previously participated in a brief alcohol intervention	Randomized trial; Group A: No IVR (81); Group B: IVR (75); Group C: IVR+feedback (75); Group D: IVR+feedback+$ (53)	Mean=45.88 36.25%	Brief intervention according to the FRAMES model, message from therapist
14. King et al. (2008) USA: Healthy, initially underactive adults aged 50 years and older	Randomized, controlled experiment; Group A: intervention (19); Group B: control (18)	Mean=60.15 42.1%	Self-regulatory strategies derived from social cognition perspective (i.e. goal setting, individualized feedback)

Outcomes	Follow-up post-intervention period
POSITIVE EFFECT: Significant increase in medication adherence (only for individuals who were living independently), number of social interactions and reduction in severity of hallucinations was found; the probability of endorsing attitudes that could interfere with improvement in these outcomes was also significantly reduced NO EFFECT: Lab-based assessments of more general symptoms and functioning did not change significantly.	No FU
POSITIVE EFFECT: The pseudo-experimental group showed a larger decrease in NA compared to the control group. NO EFFECT: The experimental group did not show a significant larger increase in momentary PA during or shortly after the intervention compared to the pseudo-experimental or control groups.	See 15
POSITIVE EFFECT: Significant between-group difference at end-of-treatment in NumDD (particularly in alcohol-dependent patients) NO EFFECT: No significant difference between MI only and MI+HealthCall in NumDD; no intervention effects on NumDD among non-alcohol-dependent patients.	12-month FU: although NumDD remained lower among alcohol-dependent patients in MI +HealthCall than others, effects were no longer significant.
POSITIVE EFFECT: messages tailored to smoking urge, cigarette availability, or stress corresponded with greater reductions in those triggers than messages that were not tailored to specific triggers. NO EFFECT: Although messages tailored to stress were associated with greater reductions in stress than messages not tailored to stress, the association was non-significant when only moments of high stress were included in the analysis.	See 8
NEGATIVE EFFECT: The IVR groups reported higher consumption on the TLFB at the 3- and 6-month follow-ups than did the no IVR group (potential measurement confound) POSITIVE EFFETCT: Reported impact of the IVR and associated feedback on drinking awareness was high. A comparison of the feedback and no feedback IVR groups (independent of potential confounder) shows a significant therapeutic advantage of IVR with feedback.	No FU
POSITIVE EFFECT: Relative to controls, intervention participants reported significantly greater 8-week mean estimated caloric expenditure levels and minutes per week in MOD+ activity.	No FU

Appendix B. Continued.

Study ID, and Population	Study Design (N), and groups	Age, and gender (% female)	Intervention elements (in addition to self-monitoring)
15. Kramer et al. (2014) NL: Pharmacologically treated outpatients with a major depression disorder	See 10	See 10	See 10
16. Kristjánsdóttir et al. (2013a) NO: Women with chronic widespread pain	Randomized trial; Group A: intervention (70); Group B: control (70)	Mean=44.56 100%	Cognitive behavioural fear-avoidance model and CBT/ACT (i.e. individual sessions; personalized feedback; guided mindfulness exercise)
17. Kristjánsdóttir et al. (2013b) NO: Women with chronic widespread pain	See 16	See 16	See 16
18. Naylor et al. (2008) USA: Subjects with chronic musculoskeletal pain	Randomized trial; Group A: intervention (26) Group B: control (25)	Mean=46.5 86%	CBT, personalized messages from therapist, didactic review of skills, guided behavioural rehearsal of pain coping skills
19. Rose et al. (2012) USA: Outpatients after treatment for substance use disorder	Single-armed pilot study (21)	Mean=45.6 43%	CBT, personalized messages from therapist, access to recorded CBT skills
20. Ruehlman et al. (2012) USA: Individuals with chronic pain	Randomized controlled trial; Group A: intervention (162); Group B: wait-listed control (143)	Mean=44.93 Range 19-78 64.3%	CBT, education, self-regulation skills, social support, progress tracking

Outcomes	Follow-up post-intervention period
POSITIVE EFFECT: Add-on ESM-derived feedback resulted in a significant and clinically relevant stronger decrease in HDRS and IDS score relative to the control group.	6-month FU: clinically relevant decrease in HDRS and IDS scores (compared to pseudo-experimental group)
POSITIVE EFFECT: Immediately after the intervention period, the intervention group reported less catastrophizing than the control group yielding a large effect size for study completers.	5-month FU: between-group effect sizes remained moderate for catastrophizing, acceptance of pain, and functioning and symptom levels.
See 16	11-month FU: NEGATIVE EFFECT: No significant between-group effect was found on the study variables POSITIVE EFFECT: within-group analyses, comparing the baseline for the smartphone intervention to the 11-month data, indicated changes in the desired direction in catastrophizing and acceptance in the intervention group but not within the control group
POSITIVE EFFECT: Intervention group showed maximum improvement over baseline at the 8-month follow-up for seven of the eight outcome measures (e.g. pain, mental health, coping, etc); improvement was found to be significant for all out-comes. Between-group analysis of covariance revealed significantly greater improvement for the experimental group at both 4- and 8-month FUs for most of the outcomes.	8-month FU: see outcomes
POSITIVE EFFCTS: Abstinence rate increased significantly during study. Both self-efficacy and coping significantly improved from pre-CBT to post-study.	No FU
POSITIVE EFFECT: Program utilization was associated with significant decreases in pain severity, pain-related interference and emotional burden, perceived disability, catastrophizing, and pain-induced fear. Further, program use led to significant declines in depression, anxiety, and stress. Compared to the wait-listed control group, the experimental group displayed a significant increase in knowledge about the principles of chronic pain and its management.	7-week and 14-week FU: see outcomes

6

Appendix B. Continued.

Study ID, and Population	Study Design (N), and groups	Age, and gender (% female)	Intervention elements (in addition to self-monitoring)
21. Ruscio et al. (2015) USA: Adult community smokers	Pilot randomized controlled trial; Group A: Brief MP (24); Group B: control sham meditation (20)	Mean=44.81 50%	Mindfulness
22. Ruscio et al. (2016) USA: Adult community smokers	See 21	See 21	See 21
23. Steinert et al. (2016) DE: Seniors with individual health-related goals	Single-armed trial (30)	Mean=68 Range 61-76 50%	Goal setting, reminders, progress tracking
24. Swendeman et al. (2015) USA: People living with HIV	Mixed-methods randomized pilot study; Group A: daily smartphone (34); Group B: bi-weekly survey (16)	Mean=45 12.2%	Progress tracking
25. Van Knippenberg et al. (2017) NL: Spousal caregivers of people with dementia	Process evaluation of Randomized controlled trial; Group A: intervention (26); Group B: pseudo-intervention (24); Group C: control (26)	Mean=72.1 67.1%	PA-focused feedback
26. Van Knippenberg et al. (2018) NL: Spousal caregivers of people with dementia	Randomized controlled trial; Group A: intervention (26); Group B: pseudo-intervention (24); Group C: control (26)	See 25	See 25

Note: RCT=randomized controlled trial; MI=motivational interviewing; NumDU=total number of days used primary drug; QuantU=total quantity of primary drug used; FU= follow-up; NIDU=non-injection drug use; HC=Healthcall; ACT/-DL=acceptance and commitment therapy (ACT) in daily life training; BMI=body mass index; COPD= Chronic obstructive pulmonary disease; CBT= cognitive behavioural therapy;

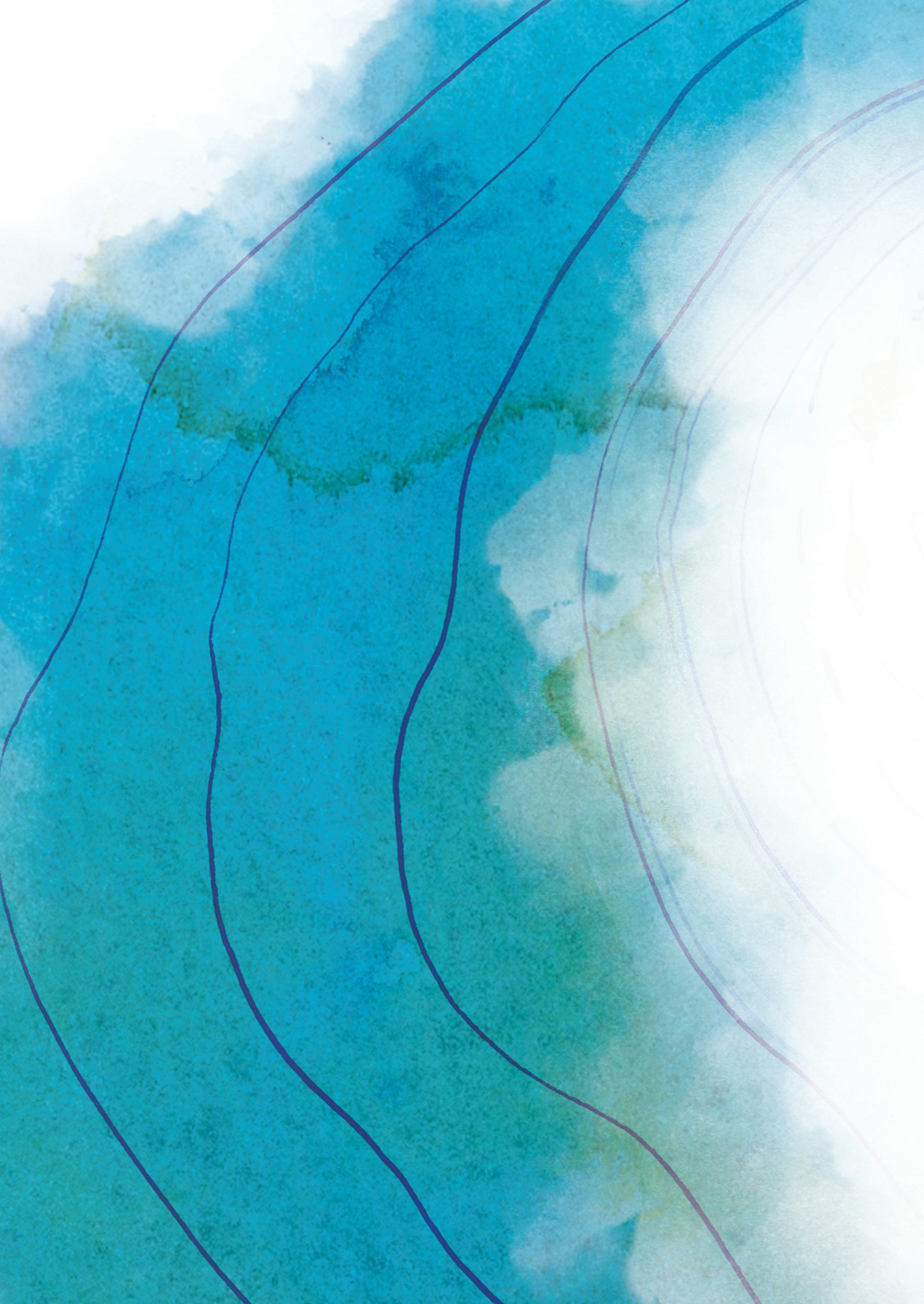
Outcomes	Follow-up post-intervention period
POSITIVE EFFECT: Linear Mixed Model analyses on EMA data revealed that Brief-MP (vs. Control) reduced overall negative affect, reduced craving immediately post-meditation, and reduced cigarettes smoked per day over time.	No FU
POSITIVE EFFECT: Linear Mixed Model analyses on EMA data revealed that, over time, Brief-MP (vs. Control) increased self-reported Curiosity and Decentering assessed by the Toronto Mindfulness Scale. NO EFFECT: Brief-MP did not change trait mindfulness or cognition.	See 21
POSITIVE EFFCTS: Significant improvements in medication adherence, nutrition, water intake (among people who drink less than 1.5l) NO EFFECT: No significant pre-to-post differences in frequency of social contacts, physical activity, or body weight.	No FU
POSITIVE EFFECT: Reported therapeutic benefits related to self-expression for catharsis, non-judgmental disclosure, and in-the-moment support. Some smartphone group participants suggested that daily self-monitoring was more beneficial than bi- weekly due to frequency and in-the-moment availability. About twice as many daily self- monitoring group participants reported increased awareness and behavior change support from self-monitoring compared to bi-weekly web-survey only participants.	No FU
POSITIVE EFFECTS: the ESM-derived feedback was considered supportive and increased participants' awareness of their feelings and behavior. 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.	2-month FU (no further information)
POSITIVE EFFECT: Postintervention, the experimental group showed a decrease in momentary negative affect compared with the pseudo-experimental and control groups. NO EFFECT: No effects were found for retrospective mastery, depression, anxiety, and momentary positive affect.	2-month FU: Both the experimental and pseudo-experimental groups showed an increase in retrospective sense of competence and a decrease in perceived stress.

PA=positive affect; NA=negative affect; NumDD= number of drinks per drinking day; IVR=interactive voice response; TLFB=Timeline Followback; ESM=experience sampling method; MOD+ = moderate intensity or more vigorous activity; HDRS=Hamilton Depression Rating Scale – 17; IDS=Inventory of Depressive Symptoms; MP=mindfulness practice

Appendix C. Health aspects monitored.

Study ID	Health aspects monitored *Physical/ behavioural/ biological*
1	Substance use, HIV-related health behaviours
2	Drug use, HIV medication adherence
3	Drug intake
4	Location, servings and types of vegetables/whole grain consumption, barriers/enabling conditions that made it more difficult/easier to eat vegetables/whole grains
5	Activity, location, quality of sleep
6	Eating-related experiences: hunger, fullness
7	Location, food consumption, COPD symptoms (breathing, coughing, sputum)
8/12	Smoking urge, cigarette availability, recent alcohol use
9	Medication adherence, auditory hallucinations
10/15	Daily life activities, physical activity, events
11	Alcohol consumption, medication adherence, wellbeing
13	Alcoholic drinks consumed, 'more general questions related to health'
14	Location, amount and types of physical activities undertaken, behavioural factors
16/17	Level and interference of pain, planned and previous use of self-management activities
18	Coping, perceived pain control, medication use
19	Anticipation of encountering high-risk situations and plan for coping with them, anticipated alcohol and drug use, drinking since last call, use of drugs since last call
20	Pain, activity
21/22	Attention bias/cognition
23	Medication intake, healthy nutrition, water control, physical activity
24	Alcohol, tobacco and other drug use, medication adherence, physical health-related quality of life
25/26	Physical well-being, activity, location, events, quality of sleep

Emotional/ psychological/ mental	*Social/ interpersonal*
Mood, stress, wellness	Sexual interactions and protection
Wellness, stress, overall quality of life	
Subjective well-being	
Mood	
Affect, cognition, appraisal of day	Company
Mindfulness ratings during eating	
Quality/appraisal of day	
Smoking urge, affect, stress, cessation motivation	
Coping strategies related to medication adherence, auditory hallucinations and socialization	Socialization
Positive and negative affect,	Social company
Reasons for not drinking, mood, wellbeing	
Motivation for use/lack of use of alcohol, mood	Relationship with partner
Motivational factors	
Depression, feelings, thoughts related to avoidance, catastrophizing,	
Coping, mood, stress	
Feelings of confidence to cope with urge and efforts to cope with urges, mood states	
Mood	
Mindfulness state, depression	
Recreational activity (take time for yourself)	Recreational activity) (cultivate social contacts)
Mental health-related quality of life, stressful events	Sexual behaviour
Negative affect, positive affect, self-esteem, sense of competence, appraisal of day	Social company



Chapter 7

Intervention Mechanisms of an Experience Sampling Intervention for Spousal Carers of People with Dementia: A secondary Analysis using momentary Data

Sara Laureen Bartels, Rosalia J.M. Van Knippenberg, Wolfgang Viechtbauer, Claudia J.P. Simons, Rudolf W. Ponds, Inez Myin-Germeys, Frans R.J. Verhey, & Marjolein E. De Vugt.

(Under review)

Abstract

Objectives: A psychosocial intervention for spousal carers of people with dementia promoted emotional well-being through self-monitoring and personalized feedback as demonstrated in a previous randomized controlled trial. The mechanism behind the intervention effects is thought to lie in increased awareness of and thus engagement in behaviours that elicit positive emotions (PA). This secondary analysis tests the assumption by investigating momentary data on activities, affect, and stress and explores the relevance of personalized feedback compared to self-monitoring only.

Methods: The intervention was based on the Experience Sampling Method (ESM), meaning that carers self-monitored own affect and behaviours 10 times/day over 6 weeks. The experimental group received personalized feedback on behaviours that elicit PA, while the pseudo-experimental group performed self-monitoring only. A control group was also included. ESM-data of 72 carers was analysed using multilevel mixed-effects models.

Results: The experimental group reported significant increases in passive relaxation activities over the 6 weeks *($B=.28$, $SE=.12$, $Z= 2.43$, $p<.05$)*. Passive relaxation in this group was negatively associated with negative affect (*$r=-.50$, $p=.01$*) and positively associated with activity-related stress (*$r=.52$, $p=.007$*) from baseline to post-intervention. Other activities in this or the other groups did not change significantly.

Conclusion: Carer's daily behaviours were only affected when self-monitoring was combined with personalized feedback. Changing one's daily behaviour while caring for a person with dementia is challenging and aligned with mixed emotions. Acknowledging simultaneously positive and negative emotions, and feelings of stress is suggested to embrace the complexity of carer's life and provide sustainable support.

Introduction

Spousal carers of people living with dementia invest time in the care with great dedication, but combining time-consuming care tasks with common day-to-day activities can be challenging. Carers spend less time on self-care, physical activity, or social interactions than non-carers, which can negatively influence carers' physical and mental health [1-4]. Contrary, engagement in enjoyable activities encompassing mental, physical, and social stimulation is associated with greater positive affect (PA) [5]. The term 'positive affect' refers to a wide range of positive emotions such as happiness, enthusiasm, and satisfaction and PA is important for coping with the challenge of caregiving as emphasized by the coping process model [6]. Especially when individuals need to cope with a stressful situation for a longer time, positive emotions support the coping process by energizing goal-directed behaviour or gaining relief from the ongoing stress [7]. Additionally, positive emotions can broaden a person's thought-action-repertoire, build their resources, and increase resilience and emotional well-being [8-10]. Psychosocial interventions for carers have shown to increase PA and thus support coping [11].

The 'Partner in Sight' Intervention and Experience Sampling Method

The 6-week 'Partner in Sight' intervention for carers of people living with dementia was designed to raise awareness for PA and related behaviours [12]. Participants self-monitored current affect, context, and activities ten times per day using a mobile device. Additionally, a coach provided the experimental group with a personalized feedback to stimulate carers to think about their daily activities and potentially redirect their behaviours towards activities that elicit more positive emotions. The pseudo-experimental group engaged in self-monitoring only and did not receive personalized feedback. A previous randomized controlled trial (RCT) showed that the intervention improved carer's emotional well-being, namely sense of competence and perceived stress, in both intervention groups [13]. However, the underlying intervention mechanism was not unravelled, as it happens in most effectiveness studies when the initial focus lies on the pre- versus post-intervention difference in outcome measures [14, 15]. The mechanism behind the improved carer's emotional well-being in the 'Partner in Sight' intervention is thought to lie in the increased awareness of, and engagement in activities that create positive emotions in the carers. Momentary data is ideally suited to map out this potential behavioural change [16].

he term 'behavioural change' is defined as a significant increase/decrease of engagement in certain daily activities. Momentary data can be collected through the so called experience sampling method (ESM), which was used in the 'Partner in Sight' intervention to enable self-monitoring with the mobile device. This momentary information can reveal daily behavioural and emotional patterns, such as which activities are related to high positive or negative affect [17-19], and illustrates the complexity of everyday life.

The Present Study

The present study aims to determine if a behavioural change was the intervention mechanism that led to improved carer's emotional well-being in the 'Partner in Sight' intervention study. This secondary approach is necessary to identify the impact the intervention had on the participant's everyday life and thus test the proposed mechanism.

Firstly, we hypothesized that the ESM self-monitoring in the 'Partner in Sight' intervention, particularly in combination with personalized feedback, would promote a behavioural change in the carers towards more enjoyable activities, such as self-care or relaxation. Therefore, the ESM-based daily activity data of carers was investigated from baseline to post-intervention as well as throughout the 6 intervention weeks. Secondly, we examined associations between the changes in behaviours (e.g., doing nothing, caregiving, active and passive relaxation, and self-care; self-defined by carer) and changes in affect as well as stress.

Materials and Methods

Participants and Design

A secondary analysis of the ESM-data of the 'Partner in Sight' intervention was performed in this study. In short, participants (n = 76) were informal dementia carers of all subtypes and stages, who were primarily recruited from memory clinics, via digital newsletters, and the website of the Dutch Alzheimer Association (Alzheimer Nederland). Inclusion criteria included being a spousal caregiver of a person living with dementia and sharing a household with the care recipient. Participants were excluded from the study if their cognitive abilities were clinically judged as insufficient to engage in ESM (inability to use the mobile device) or if caregivers felt overburdened or had severe health problems. All participants provided written informed consent. The Medical Ethics Committee of the Maastricht University Medical Centre Plus approved the study (#143040). A more detailed summary of the design of the 'Partner in Sight' RCT and the effectiveness of the intervention can be found elsewhere [12, 13].

The complete original study protocol included a baseline assessment, a 6-week intervention period, a post-intervention assessment, and 2- and 6-month follow-up assessments. A RCT was conducted with three treatment arms, including an experimental group, a pseudo-experimental group, and a control group. Of interest in the present study is the ESM-data from the baseline assessment, intervention period, and post-intervention assessment.

Participants in the experimental and pseudo-experimental group were asked to complete the ESM-questionnaires for three consecutive days at baseline, in each intervention week, and during the post-intervention assessment. The experimental group additionally received personalized feedback (see '*Intervention*' section for details). The control arm provided ESM-data only at baseline and for the post-intervention assessment and continued with care as usual during the intervention period. Figure 1 provides a graphical overview of the intervention elements per group.

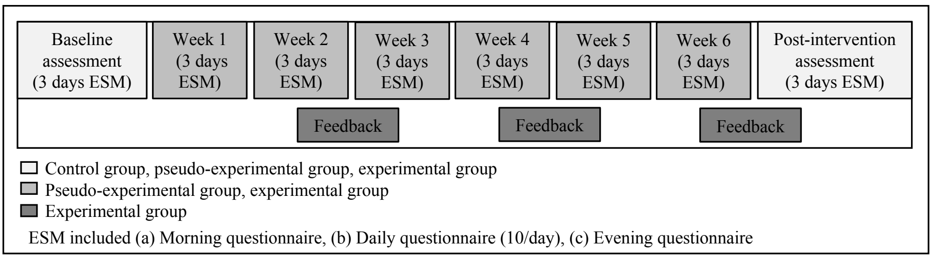


Figure 1. 'Partner in Sight' intervention elements per group focusing on the experience sampling method (ESM) assessments.

Intervention

The program 'Partner in Sight' ran over six consecutive weeks. Both the experimental and the pseudo-experimental group engaged in ESM self-monitoring. On self-monitoring days, the ESM-questionnaire was filled in ten times per day, for a total of 30 time-points at baseline and post-intervention (10 beeps × 3 consecutive days) and 180 time-points during the intervention period (10 beeps × 3 consecutive days × 6 weeks). A 'beep' is a signal (sound and vibration) given by the mobile device at random time intervals between 7:30AM and 10:30PM, prompting the participant to answer the ESM-questionnaire. Additionally, a morning and evening ESM-questionnaire asked the participants to reflect on the previous night and day, respectively. The 'PsyMate' mobile device was used to collect the data, and its feasibility in dementia carers has been demonstrated [20]. ESM included questions on current mood, behaviours, and context. The full ESM-questionnaire can be found in the Appendix (Table 1).

Additionally, the experimental group received face-to-face feedback from a coach every 2 weeks. The reason for having two intervention groups was to investigate the added benefit of personalized feedback compared to self-monitoring only. Each feedback session followed a standardized protocol. Feedback was provided both verbally and graphically by a personal coach (i.e., psychologist) on the contexts and activities and their relation to the levels of PA experienced in daily life. Also, changes in daily average PA during the intervention period were discussed and thus positively reinforced as part of the motivational coaching. A summary of the feedback was handed out to each participant. An example of the feedback graphs can be found in the Appendix (Figure 1).

Measures

Baseline assessment

The sociodemographic information of the carer and the person living with dementia was assessed at baseline, including age, sex, profession, and level of education. Additional information and the full list of baseline questionnaires, which are not part of the present post-hoc analysis, can be found elsewhere [13].

ESM assessments

To include different days of the week, the 'PsyMate' mobile device beeped alternately on Friday, Saturday, and Sunday, or Tuesday, Wednesday, and Thursday during the intervention period. Behaviours were assessed with the following question: 'What am I doing?'. Participant could choose one or more activities from the following categories: 'doing nothing', 'work', 'household', self-care', 'caring for partner', 'active relaxation', 'passive relaxation', and 'something else'. These daily behaviours were chosen in the daily questionnaires based on previous ESM-based studies as the most common daily behaviours [21, 22] and 'caring for partner' was added. The present study focuses on the occurrence (0 or 1) of doing nothing, self-care behaviour, active and passive relaxation, and caregiving behaviour. Participants defined the behaviours subjectively.

PA, NA, and activity-related stress were measured on a 7-point Likert scale ranging from 1 (not at all) to 7 (very) ten times per day. The level of momentary PA was defined by the mean score of the following four items: 'I feel cheerful', 'I feel relaxed', 'I feel enthusiastic', and 'I feel satisfied'. Momentary NA resulted from the ESM items 'I feel insecure', 'I feel lonely', 'I feel anxious', 'I feel irritated', 'I feel down', 'I feel desperate', and 'I feel tensed'.

Activity-related stress included the items 'I like doing this' (reversed-scored), 'I would rather be doing something else', 'This is difficult for me', and 'I can do this well' (reversed-scored). The activity-related stress items were based on the appraisal theory [23] declaring that for an activity to be stressful, it has to be perceived as negative and challenging, while the person experiences a lack of skills to cope with it [24]. The mean PA, NA, and activity-related scores were calculated for each completed beep during the day with a higher score indicating higher levels of affect or stress. The reliability of PA, NA, and activity-related stress are presented on a between- and within-person level in the results section.

Statistical analysis

The presented analyses were performed post-hoc. Multilevel (i.e., mixed-effects) models were used for the analysis, with level one corresponding to the daily ESM assessments nested within individuals on level two. The experimental and pseudo-experimental group were analysed separately as the 'Partner in Sight' program had previously been shown to affect the groups unequally [13], and thus group differences were expected. First, the intervention groups were compared to the control group. The models included a dummy variable for time (pre-/post-intervention), a dummy variable for treatment allocation (group), and the interaction between time and treatment allocation as fixed effects. Additionally, the behavioural change over the course of the intervention was analysed for the two ESM self-monitoring groups and seen as a 'growth' in behaviour [16]. The analyses included behaviour during the ESM intervention as the dependent variable and time in 2-week blocks (weeks 1-2, 3-4, and 5-6) as a fixed effect. In this part of the analysis, time was operationalized through a dummy variable that reflected the course of the intervention (1 = weeks 1 and 2, 2 = weeks 3 and 4, 3 = weeks 5 and 6). The 2-week blocks were chosen as the feedback was given every two weeks (Figure 1). The control group was not included in this sub-analysis as ESM-data were only available at baseline and post-intervention.

The second main analysis focused on the associations between behavioural change and changes in PA, NA, and activity-related stress from baseline to post-intervention in the intervention groups individually. For this, first multilevel logistic regression models for the dichotomous behaviours were fitted (occurrence 0 or 1) as the dependent variable, and a time variable as a fixed effect. Time was here operationalized through a dummy variable of the baseline and post-intervention 3-day ESM assessments (0 = baseline t = 1…30; 1 = post-intervention t = 31…60). Second, linear mixed-effects models were used to analyse PA, NA, and activity-related stress as the dependent variables, with time (see above) as a fixed effect.

Based on these models, the best linear unbiased predictions (BLUPs) were extracted to estimate subject-specific slopes corresponding to the changes in the various behaviours and the changes in PA, NA, and activity-related stress. Finally, the subject-specific slopes were correlated between the changes in behaviour and change in affect or stress.

Behaviour: $logit\ (\Pr(y_{it} = 1) = \alpha_{0i} + \alpha_{1i} * time_i$

Affect/stress: $y_{it} = \beta_{0i} + \beta_{1i} * time_{it} + \varepsilon_{it}$

Correlating the slopes: $corr\ (\widehat{\alpha_{1\iota}}, \widehat{\beta_{1\iota}})$

In the RCT, changes in stress levels were only determined using retrospective measures. Therefore, we included a sub-analysis to determine the change in activity-related stress from baseline to post-intervention in the intervention groups using the momentary data. A linear mixed-effects model was used, with activity-related stress as the dependent variable and time as a fixed effect. Time was here again operationalized through a dummy variable (0 = baseline t = 1…30; 1 = post-intervention t = 31…60).

All models included a random intercept for participants, a random slope for the time variable (dummy variable for either baseline and post-intervention or intervention weeks in two-week blocks), and an unstructured variance-covariance matrix for random effects. The alpha level was set to 0.05 throughout all analyses. For all statistical analyses, the statistical program Stata (version 13.0) was used.

Results

Participants

At baseline, approximately two-thirds of the total sample (67.1%) were female (n=76 carers). The age of the participants ranged from 43 to 88 years (mean, 72.1 ± 8.39 years). About half (51.3%) were low-educated (primary education, including lower vocational), 19.7% medium-educated (secondary education, including intermediate vocational), and 28.9% highly educated (higher education, including higher vocational and bachelor's, graduate, and doctoral degrees). All participants lived with their partner with dementia at home, and nearly all were retired/not working (96.1%). There were no significant differences in the sociodemographic information between the groups at baseline. A flow-chart of study participation and reasons for drop-outs have previously been reported [13].

General ESM assessments

Participants had to provide sufficient ESM data to be included in this secondary analysis (>10 valid beeps during baseline/post-intervention, > 60 beeps during the intervention [13]). Subjects not meeting this requirement were excluded from this analysis. Therefore, seventy-two participants were included in the present post-hoc analysis (n = 72 at baseline, n = 42 during intervention, n = 60 at post-intervention). Participants completed in total 8488 valid ESM questionnaires, 1660 at baseline, 5481 during the intervention, and 1347 at post-intervention. On average per person, 23 ESM assessments were completed during the baseline period, 134 ESM assessments during the intervention period, and 18 ESM assessment during the post-intervention period. The within- and between-person reliability measures (Cronbach's alpha) of PA, NA, and activity-related stress at baseline/post-intervention and the 6-week intervention period are presented in Table 1. The percentages and means of carers' daily behaviours, affect, and activity-related stress at baseline and post-intervention for all three groups are presented in Table 2.

Table 1. Reliability of the repeated measures across all groups.

	Baseline/post-intervention period		**Six-week Intervention period**	
Beep-level (within-person)	PA	α=0.86	PA	α=0.85
	NA	α=0.79	NA	α=0.76
	Activity-related stress	α=0.60	Activity-related stress	α=0.68
Person-level (between-person)	PA	α=0.97	PA	α=0.96
	NA	α=0.96	NA	α=0.95
	Activity-related stress	α=0.86	Activity-related stress	α=0.83

PA=positive affect, NA=negative affect. Note: Baseline/post-intervention includes the experimental, pseudo-experimental, and control group; the 6-week intervention period includes the experimental and pseudo-experimental group

Table 2. Carers' daily behaviours, PA, NA, and activity-related stress at baseline and post-intervention.

Variable	Treatment	Percentage/mean (SD)	
		Baseline	Post-intervention
Caregiving	Experimental	19.50	22.30
	Pseudo	12.95	20.67
	Control	16.67	21.91
Active relaxation	Experimental	12.52	12.80
	Pseudo	12.57	11.64
	Control	14.76	12.90
Passive relaxation	Experimental	19.68	26.93
	Pseudo	22.29	24.94
	Control	25.35	23.26
Self-care	Experimental	12.52	14.35
	Pseudo	10.67	12.59
	Control	12.15	11.42
Doing Nothing	Experimental	17.89	19.87
	Pseudo	20.57	18.05
	Control	24.48	26.64
Positive affect	Experimental	4.84 (1.33)	5.08 (1.24)
	Pseudo	5.00 (1.38)	4.87 (1.46)
	Control	4.68 (1.41)	4.51 (1.48)
Negative affect	Experimental	1.89 (1.03)	1.57 (0.77)
	Pseudo	1.89 (1.10)	1.79 (1.28)
	Control	2.05 (1.26)	1.98 (1.14)
Activity-related Stress	Experimental	2.95 (1.25)	2.57 (1.32)
	Pseudo	2.70 (1.20)	2.55 (1.11)
	Control	2.81 (1.23)	2.84 (1.29)

Pre-post changes of behaviour and growth over the 6-week intervention period

Only the experimental group showed a significantly higher pre-to-post increase compared to the control group in one daily behaviour, namely passive relaxation ($B = 0.60$, $SE = 0.30$, $Z = 1.99$, $p < 0.05$). No significant differences in average change of behaviour were found in caregiving, active relaxation, self-care, or doing nothing in either of the two ESM self-monitoring groups in comparison to the control group (Table 3).

Passive relaxation showed a linear growth over the 6-week course of the intervention in the experimental group. An average increase in the log-odds of passive relaxation by 0.28 every 2 weeks ($B = 0.28$, $SE = 0.12$, $Z = 2.43$, $p < 0.05$) was detected, while the pseudo-experimental group showed a non-significant trend of growth in the same activity ($B = 0.18$, $SE = 0.11$, $Z = 1.67$, $p = 0.09$). The other activities did not show a significant growth over the 6-weeks in either of the intervention groups [Experimental group: doing nothing ($B = -0.17$, $SE = 0.22$, $Z = -0.76$, $p = 0.45$), self-care ($B = 0.00$, $SE = 0.08$, $Z = 0.05$, $p = 0.96$), active relaxation (B

= 0.08, *SE* = 0.10, *Z* = 0.76, *p* = 0.45), caregiving (*B* = 0.03, *SE* = 0.17, *Z* = *0.15*, *p* = 0.88); Pseudo-intervention group: doing nothing (*B* = -0.05, *SE* = 0.12, *Z* = -0.41, *p* = 0.68), self-care (*B* = 0.12, *SE* = 0.12, *Z* = 1.00, *p* = 0.32), active relaxation (*B* = -0.04, *SE* = 0.14, *Z* = -0.26, *p* = 0.8), caregiving (*B* = 0.08, *SE* = 0.15, *Z* = 0.54, *p* = 0.59)].

Table 3. The effect of time (dummy variable for baseline/ post-intervention) on behaviours (frequency per day) for the ESM intervention groups compared with the control group (reference group).

Dependent variable	Treatment allocation	Time x Treatment		
		B (SE)	*Z*	*p*
Caregiving	Experimental	-.20 (.36)	-.55	.58
	Pseudo	.33 (.37)	.89	.38
Active relaxation	Experimental	.13 (.42)	.30	.76
	Pseudo	-.10 (.43)	-.24	.81
Passive relaxation	Experimental	.60 (.30)	1.99	<.05
	Pseudo	.22 (.31)	.72	.47
Self-Care	Experimental	.29 (.29)	.99	.32
	Pseudo	.21 (.30)	.69	.49
Doing Nothing	Experimental	.03 (.41)	.06	.95
	Pseudo	-.40 (.42)	-.96	.34

Associations between changes in behaviours and affect as well as activity-related stress

All associations between two variables reflect the change from baseline to post-intervention in behaviour, affect, or activity-related stress. In the experimental group, passive relaxation was negatively associated with NA (*r* = -0.50, *p* = 0.010) and positively associated with activity-related stress (*r* = 0.52, *p* = 0.007). The other behaviours did not show significant associations with PA, NA, or activity-related stress in the experimental group.

7

In the pseudo-experimental group, doing nothing (PA: *r* = 0.64, *p* = 0.001; NA: *r* = -0.46, *p* = 0.03) and self-care (PA: *r* = 0.55, p = 0.009; NA: *r* = -0.45, *p* = 0.034) were both positively associated with PA and at the same time negatively associated with NA. Caregiving was negatively associated with PA (*r* = -0.43, *p* = 0.047). All other behaviours did not show a significant association with affect and stress in the pseudo-experimental group (Table 4).

Activity-related stress showed a significant decrease from baseline to post-intervention in the experimental group (*B* = -0.24*, SE* = 0.08*, Z* = -2.95*, p* < 0.01), while there was no significant change in activity-related stress in the pseudo-experimental group (*B* = -0.11, *SE* = 0.13*, Z*= -0.83*, p* = 0.41).

Table 4. Associations between behaviours and affect as well as activity-related stress.

	Experimental group						*Pseudo-experimental*					
	PA		*NA*		*a.-r. stress*		*PA*		*NA*		*a.-r. stress*	
	r	*p*	*r*	*p*	*r*	*p*	*r*	*p*	*r*	*p*	*r*	*p*
Doing Nothing	-.21	.32	.16	.44	.01	.97	**.64**	**.001**	**-.46**	**.03**	-.40	.07
Passive Relaxation	.25	.23	**-.50**	**.01**	**.52**	**.007**	-.01	.96	.04	.87	.07	.75
Active Relaxation	-.03	.87	.19	.34	-.09	.68	-.16	.47	.09	.71	-.01	.98
Self-Care	-.36	.07	.13	.52	.17	.43	**.55**	**.009**	**-.45**	**.034**	.06	.80
Caregiving	.07	.75	.03	.88	.05	.81	**-.43**	**.047**	.10	.66	.08	.74

PA= positive affect; NA=negative affect; a.-r. stress= activity-related stress. Note: The subject-specific slopes from baseline to post-intervention of behaviour; here, affect and stress are correlated.

Discussion

This study evaluates behavioural change as the underlying mechanism of the previously described intervention effect of Partner in Sight, namely improved emotional well-being in spousal carers of people living with dementia. The ESM data provided a detailed and complex picture of carer's daily behaviours, affect, and stress, adding relevant information to the effectiveness study of the 'Partner in Sight' intervention [13].

First, this study showed that the 'Partner in Sight' intervention resulted in a behavioural change of one activity in the experimental group, namely an increase in passive relaxation throughout the intervention. Passive relaxation was self-defined by the carer and included various leisure activities, such as watching TV or reading, also in combination with other activities such as traveling or household activities. From baseline to post-intervention, spending more time in passive relaxation was strongly associated with increased activity-related stress and decreased NA. Overall, these associations indicate mixed feelings in the carers during the behavioural change towards more passive relaxation in everyday life.

Behavioural Adaptation and Mixed Emotions during Caregiving

Leisure as a 'free or unobligated time that does not involve work or performing other life-sustaining functions' (p.3) [25] includes passive relaxation. Due to personal preferences, the form of leisure can vary, and carers might pursue a wide range of activities that provide respite [26]. Leisure can have a therapeutic effect and be a coping mechanism for carers [27]. Satisfaction with leisure experienced by the carer is suggested to act protectively against certain health risks [28]. Therefore, interventions for carers may promote more engagement in leisure as a form of self-care to protect or improve well-being.

Following this well-meant advice to do more enjoyable activities, however, can be more challenging for carers of people living with dementia than health professionals might expect. Caregiving can be accompanied by feelings of inseparability between the carer and care recipient, which has been described as a 'progressive compensatory symbiosis' [29]. In such a situation, pursuing one's own leisure might be hindered by both external and internal barriers [30].

In the present study, one external factor might have been the presence of the person living with dementia during passive relaxation, which was the case 60% of the time as background analysis revealed. It might have been difficult for the carer to relax in an adequate atmosphere when the care recipient expressed needs that interfered. Forty percent of the time, when the person living with dementia was absent, an internal dilemma could have occurred, including feelings of guilt, restriction, or dissatisfaction. The entitlement to leisure can be an intractable concept for carers, and the sense of obligation to the care recipient might make all leisure meaningless [31]. Bedim and Guinan [32] suggest that the sense of responsibility to the care recipient can outweigh the carer's own personal and leisure needs. Furthermore, even though many carers express a desire for leisure, they may feel that leisure is not doable while embodying their helping roles. Some carers might suppress their desire for leisure or feel frustrated over the inability to access leisure satisfactorily, while others might include the care recipient into leisure activities, or find a way to pursue leisure activities by justifying it as important to fulfil the caregiving role [32].

Unfortunately, leisure activities offered for both the carer and person living with dementia together are rarely available, leading to social injustice [33]. This lack of external offers can further complicate efforts to combine caregiving and own leisure. The dilemmas illustrated might indicate that carers experience it as difficult to act on the advice from healthcare professionals to 'take care', which could be generally beneficial.

External and internal barriers could explain the feelings experienced by the carers in the present study, namely a strong decrease of NA and a simultaneously strong increase in activity-related stress when spending more time in passive relaxation. PA did not change significantly in relation to passive relaxation. Generally, ESM data are known to describe complex pictures of feelings, and PA and NA can change disproportionally, as they can be seen as two separable constructs rather than two extremes of a binary continuum [34]. In the elderly, experiencing both PA and NA simultaneously could be an indicator for a typical or adaptive emotional state in a stressful situation [35]. Future interventions need to keep individual factors, such as leisure type, age, personality, and other external and internal barriers in mind when promoting leisure to carers.

In the present study, the process of behavioural change was complex and stressful for the carers, but overall the 'Partner in Sight' program led to positive intervention effects, such as a retrospectively measured decrease in perceived stress and an increase in the sense of competence, as well as ESM-measured decrease of NA [13]. Moreover, the present study showed that the ESM-measured activity-related stress generally decreased throughout the intervention. This finding suggests that, while the process of change was stressful, more leisure itself can be stress-releasing.

Personalized Feedback Promoting Behavioural Change in Carers

For carers of people with dementia, the personalized feedback focusing on PA and daily activities seems crucial in their behavioural change process as only the experimental group reported a change. Figure 2 illustrates the intervention mechanisms as suggested in change pathways: (digital) self-monitoring of daily functioning led to increased attention to and awareness of own emotions and behaviours. This awareness directly promotes an emotional change as both the pseudo-experimental and the experimental group showed a decrease in retrospectively measured perceived stress, an increase in the sense of competence, and a decrease in ESM-measured NA as shown in the RCT [13].

Only when the awareness gained through the self-monitoring was combined with personalized feedback focusing concretely on daily activities that elicit PA, a change in behaviour could be promoted in the participating carers. This findings is contrary to a study with a similar set-up for outpatients with depression, in which both intervention groups with and without personalized feedback reported a behavioural change [16]. Potentially, the personalized feedback gave a concrete impulse and increased the carer's motivation to adapt the current situation. The behaviour change process was then challenging but resulted in increased engagement in enjoyable activities. However, carers in this study only engaged more in one activity. Eventually, more frequent personalized feedbacks could have achieved a greater behavioural change. In the mentioned intervention for patients with depression, participants received weekly personalized feedback and changes in multiple activities could be observed [16]. While carers of people with dementia also experience depressive symptoms [36], their circumstances are likely to be different from the circumstances of patients with depression. Nevertheless, weekly personal feedback may be useful for cares and could also improve the sustainability of intervention effects [37].

There are a great number of theories attempting to explain behavioural change [38]. However, none of these theories focus specifically on spousal carers of people with dementia. Raising awareness for PA and related behaviours through self-monitoring and feedback could be a key factor and mechanism to support coping in this population as illustrated in the change pathways. Future research is needed to follow-up on additional needs carers might have and explore the optimal amount of personalized feedback to achieve sustained coping during caregiving.

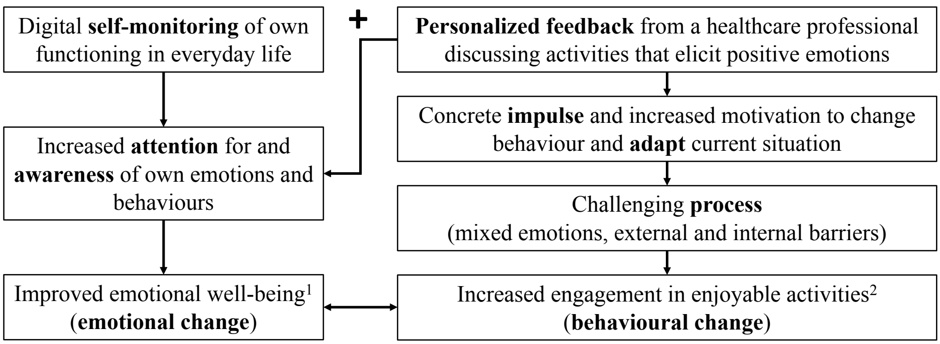


Figure 2. Intervention mechanisms explained through change pathways (based on the 'Partner in Sight' intervention elements for spousal carers of people with dementia).
[1]Findings from RCT; [2]Findings from present study.

Methodological considerations

The uniqueness of this study is characterized by the in-depth assessment of carers' everyday life before, during, and after an intervention. However, there are also general limitations to this study. First, the issue of reactivity should be considered when interpreting the results of ESM studies. The randomized time schedule was chosen to desensitize carers to the momentary assessments and thus minimize the risk for negative reactivity and preparation for completing the ESM questionnaire [39]. Nevertheless, it is acknowledged that repeated measures can lead to unusual attention to ones' internal states and behaviour [40]. Second, the directionality of the relationship between behaviour, affect, and stress remains unclear. It is not possible to conclude from the present findings if behaviour influences feelings or vice versa. Furthermore, ESM-data collection daily over the 6-week program would have allowed for an even better depiction of everyday experiences in carers. This, however, could have been too burdensome for the participants, and thus the decision was made for only three days of sampling per week. The adherence seems to already decrease over the course of the intervention, which supports the choice for the present study design. Finally, we acknowledge the potential selection bias during recruitment as only carers who experienced low- to medium-burden might have participated, limiting the generalisation of our results.

Conclusion

This study describes the complex picture of carer's everyday life and elaborates on the intervention mechanisms of the 'Partner in Sight' intervention. An ESM-intervention in combination with personalized feedback focusing on daily activities that elicit positive emotions can enable a behavioural change towards more passive relaxation. This behavioural change process, however, is accompanied by mixed feelings. Clinicians and researchers are advised to keep the complexity of the situation in mind when suggesting more self-care and leisure to dementia carers to improve their well-being. Personal contact is highly recommended to support carers in their daily tasks. Adapting one's daily activities while providing care for a relative living with dementia seems to be complex and challenging, just like caregiving itself.

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Appendix.

Table 1. Description of the ESM 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’)

Table 1. Continued

Daily questionnaire		
Concept	**Item**	**Rating scale**
	29. I am doing this activity together with my partner	Yes; no
Location	30. Where am I?	At home; at family's/friend's place; at work; health care setting; public place; transport; somewhere else
Social company	31. Who am I with?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/ others; nobody
	32. With whom else?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/ others; nobody
	33. And…?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/ others; nobody
	Branching questions in case of being in company:	
	34. I would prefer to be alone	7-point scale (1 'not at all' to 7 'very much')
	35. I think my company is pleasant	7-point scale (1 'not at all' to 7 'very much')
	36. I feel at ease in this company	7-point scale (1 'not at all' to 7 'very much')
	Branching questions in case of being alone:	
	34. I would prefer to be in company	7-point scale (1 'not at all' to 7 'very much') of others
	35. I enjoy being alone	7-point scale (1 'not at all' to 7 'very much')
	36. I feel at ease being alone	7-point scale (1 'not at all' to 7 'very much')
Events	37. Since the last alert the most important 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')

Table 1. Continued

Morning questionnaire		
Concept	**Item**	**Rating scale**
	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’)
	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	7-point scale (1 ‘not at all’ to 7 ‘very much’)
	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’)

Table 1. Continued

Evening questionnaire		
Concept	**Item**	**Rating scale**
	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')

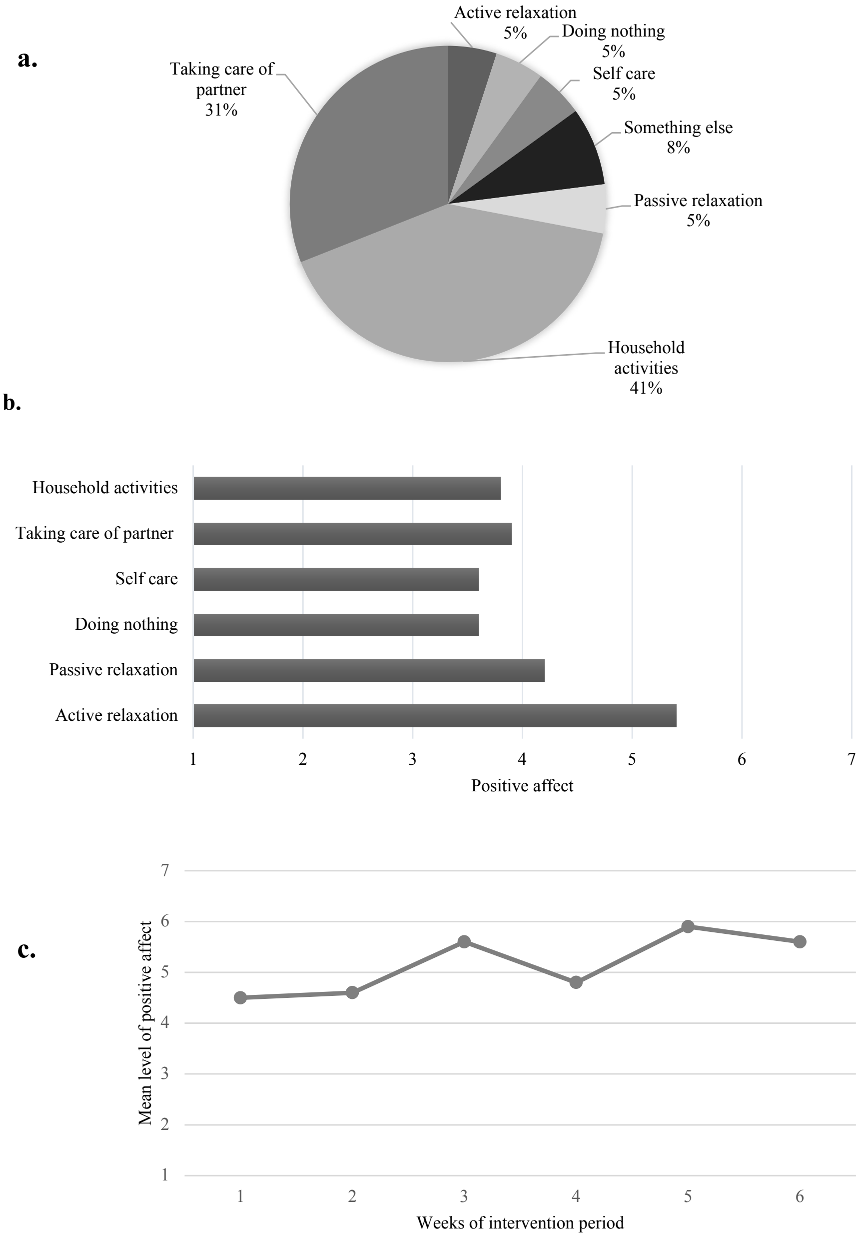
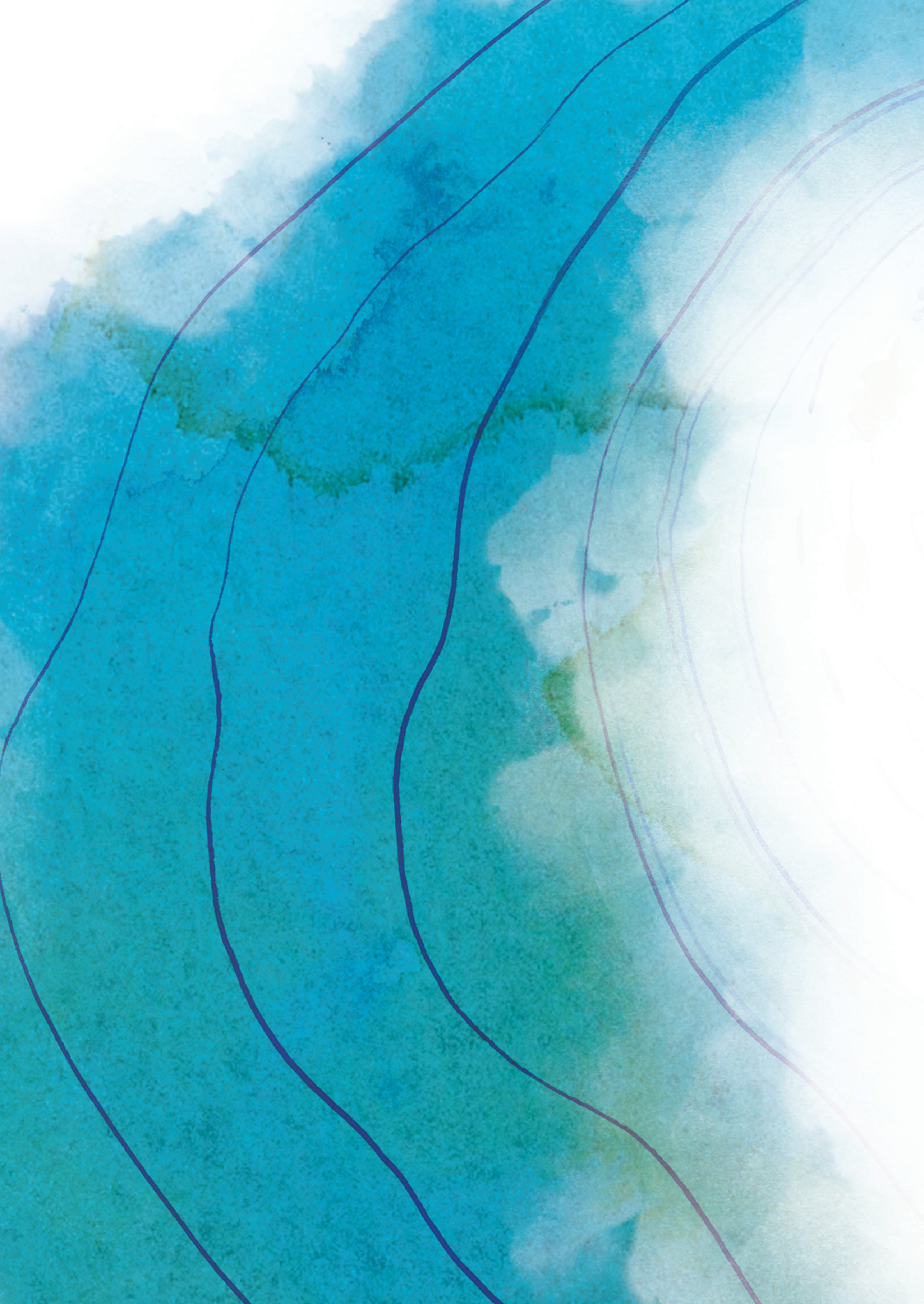


Figure 1. Examples of ESM-based feedback graphs. (a.) Amount of time spend doing different types of activities; (b.) Amount of positive affect experienced per type of activity; (c.) Mean level of positive affect over the six-week intervention period.
Note: This graph has previously been published **(Chapter 8)**



Chapter 8

The Necessity for Sustainable Intervention Effects: Lessons-learned from an Experience Sampling Intervention for Spousal Carers of People with Dementia

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Abstract

Objectives: Caring for a person with dementia can be challenging over the years. To support family carers throughout their entire caregiving career, interventions with a sustained effectivity are needed. A novel six-week mobile health (mHealth) intervention using the experience sampling method (ESM) showed positive effects on carers' well-being over a period of two months after the intervention. In this study, the effects after six months of the self-same intervention were examined to evaluate the sustainability of positive intervention effects.

Method: The six-week mHealth intervention consisted of an experimental group (ESM self-monitoring and personalized feedback), a pseudo-experimental group (ESM self-monitoring without feedback) and a control group (providing regular care without ESM self-monitoring or feedback). Carers' sense of competence, mastery and psychological complaints (depression, anxiety and perceived stress) were evaluated pre- and post-intervention as well as at two follow-up time points. The present study focuses on the six-month follow-up data (n=50).

Results: Positive intervention effects on sense of competence, perceived stress and depressive symptoms were not sustained over six-month follow-up.

Conclusion: The benefits of this mHealth intervention for carers of people living with dementia were not sustained over a long time. Similarly, other psychosocial interventions for carers of people with dementia rarely reported long-lasting effects. In order to sustainably contribute to carers' well-being, researchers and clinicians should continuously ensure flexible adjustment of the intervention and consider additional features such as ad-hoc counselling options and booster sessions. In this regard, mHealth interventions can offer ideally suited and unique opportunities.

Introduction

The reduction of independent functioning of a person with dementia (PwD) results in the need for assistance. This demand is often carried out by a family carer [1]. Caring for a loved one living with dementia is a potentially rewarding [2] but long-term task that can be time-consuming and challenging due to experienced stress, negative affect or social isolation [3-5]. Therefore, interventions with sustained positive effects are needed to support carers of PwD throughout their entire caregiving career.

The overall impact of psychosocial interventions for carers of PwD seems promising[6], even though the effectiveness varies strongly between approaches such as educational interventions, dementia specific therapies, group or individual carer coping strategies or behavioural management techniques [4, 7].

To assist carers of PwD outside the clinical setting in everyday life, the intervention 'Partner in Sight' was developed based on the experience sampling method (ESM) delivered by a mobile device. Carers monitored activities, mood, and context in everyday life autonomously and, supported by a coach-guided feedback, got insight into their feelings and personal strength. Two months after the mobile health (mHealth) intervention, carers' well-being was shown to be positively influenced on outcome measures of sense of competence, perceived stress and depressive symptoms [8]. We expected these positive effects to sustain further as an ESM intervention for depressed outpatients with a similar design showed benefits over a period of six months post-intervention [9].

The aim of the present study is to evaluate the sustainability of the above-mentioned beneficial effects of the ESM intervention for carers at a six-month follow-up. The results will be discussed in relation to other psychosocial interventions leading to a reflection about the necessity for a sustainable approach in psychosocial interventions for carers of PwD.

Methods

Participants and Design

Details of the ‘Partner in Sight’ randomized control trial have been described elsewhere [8]. In brief, informal carers of PwD of all subtypes and stages were recruited from December 2014 to June 2016. Recruitment took place in the Netherlands through memory clinics, other care institutes as well as the digital newsletter and website of the Dutch Alzheimer Association (Alzheimer Nederland). Inclusion criteria included being a spousal carer of a PwD, sharing a household with the care recipient, and providing written informed consent. Participants were excluded from the study if cognitive abilities to engage in ESM seemed insufficient, if carers felt overburdened or had severe health problems based on clinical judgment of a knowledgeable practitioner.

A single-blinded randomized controlled trial was conducted with three treatments arms including an experimental group (ESM self-monitoring and personalized feedback), a pseudo-experimental group (ESM self-monitoring only), and a control group (providing regular care without ESM self-monitoring or feedback). The Medical Ethics Committee of the MUMC+ (#143040) approved the study. It is registered in the Dutch Trial Register (NTR4847).

Procedure

A telephone screening ensured study eligibility to participate. Furthermore, the study protocol contained a baseline assessment (T0), a six-week intervention period, a post-intervention assessment (T1), a two- (T2), and a six-month (T3) follow-up assessment. At T0, T1, T2, and T3, the questionnaires selected as primary and secondary outcome measures were filled in by the participants. Figure 1 illustrated the general procedure and moments of data collection.

Intervention

The program ‘Partner in Sight’ ran over six consecutive weeks. Both the experimental (at baseline n= 26) and the pseudo-experimental group (at baseline n=24) self-monitored mood (e.g. positive and negative affect) and context (e.g. activities, social company and location) for three days in a row each week. The experimental group received face-to-face feedback from a coach every two weeks including a verbal and graphically visualized overview of the personal data of the previous two weeks. Each feedback session followed a standardized protocol. The focus lay on the identification and highlighting of positive affect experienced during activities and social interactions in daily life. For example, a carer might have experienced high levels of positive affect during active relaxation activities but did actually spend very little time on this activity. The coach then stimulated the carer to think about this finding and potentially redirect behaviours towards activities related to more positive emotions. In addition, changes in daily average positive affect during the intervention period were discussed and thus positively reinforced as part of the motivational coaching. Figure 2 illustrates an example of the ESM-based feedback. The summarized feedback was handed out to each participant and clinicians involved (health care professionals involved in the treatment for the PwD and who approached the carer to participate in the study).

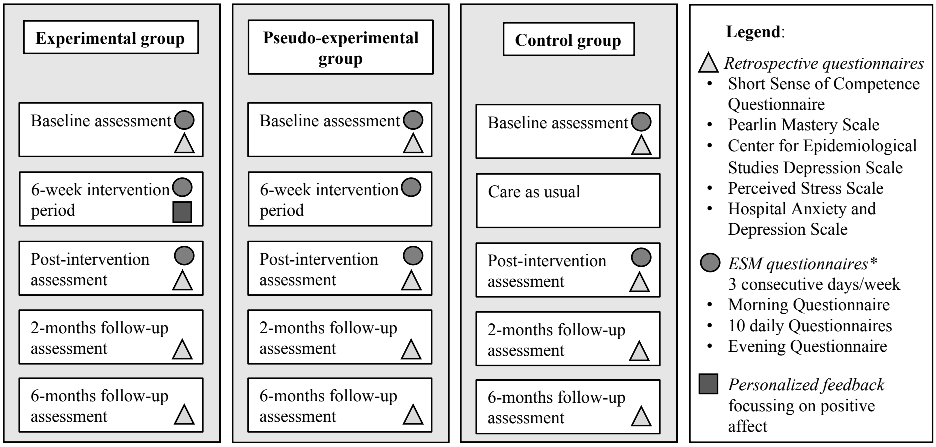

Figure 1. 'Partner in Sight' intervention, general overview of the three groups and main intervention elements (the full ESM questionnaire can be found in Appendix 1.)*

The pseudo-experimental group was similar in the ESM procedure including face-to-face sessions, except that no feedback was provided during these sessions. Instead, a semi-structured interview was conducted focused on the participant's wellbeing during the previous two weeks (i.e. SSCQ, PSS, PMS, CES-D, HADS, and NPI-Q; details see 'Instruments'). The ESM responses were not discussed when mentioned by the carer, but issues with the use of the PsyMate or unclear ESM items were addressed.

All face-to-face counselling sessions of both intervention groups took place at the participant's home. In the experimental group, the feedback sessions took about 90 minutes, while the face-to-face session in the pseudo-experimental group lasted for about 60 minutes. The control group (at baseline n=26) did not take part in the intervention but continued with regular care.

Experience sampling methodology (ESM)

ESM self-monitoring of mood and context was conducted with the 'PsyMate' mobile device (www.psymate.eu). The 'PsyMate' has been used in diverse populations [10, 11] and is feasible for carers of PwD [12].

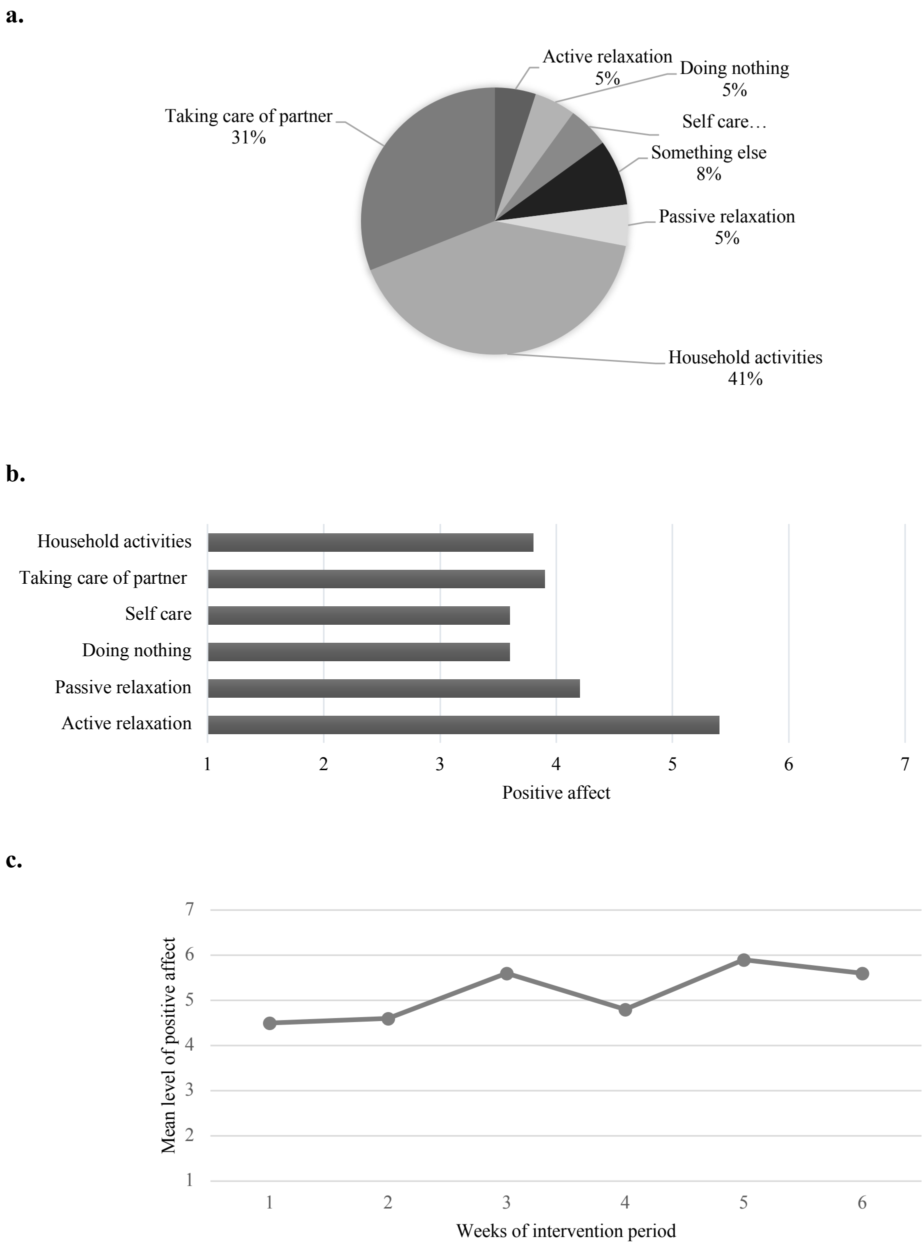

Figure 2. Examples of ESM-based feedback graphs. (a.) Amount of time spend doing different types of activities; (b.) Amount of positive affect experienced per type of activity; (c.) Mean level of positive affect over the six-week intervention period.

During the six-week intervention period, participants used the 'PsyMate' as a digital diary to fill in structured questionnaires about mood and context ten times per day on three consecutive days, with a total amount of n=180 (10 beeps x 3 consecutive days x 6 weeks). Positive affect as part of the mood questions was defined as the mean score of the items 'I feel cheerful', 'I feel relaxed', 'I feel enthusiastic', and 'I feel satisfied'. The full ESM item list can be found in appendix 1. Of the 50 participants, 39 (78.0%) participants in the experimental or pseudo-experimental group fully completed the six-week intervention period (6 x 3 ESM assessment days and three corresponding face-to-face sessions). 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% [8].

Instruments

Baseline assessment

Sociodemographic information of the carer and the PwD were assessed at baseline including age, gender and the level of education. The severity of dementia was measured by the Clinical Dementia Rating Scale (CDR) [13].

Primary outcomes

Carers' sense of competence and mastery were chosen as primary outcomes measured with retrospective questionnaires. The Short Sense of Competence Questionnaire (SSCQ) reflects the carer's sensation of being capable to care for the person with dementia. It consists of seven items and total scores range from 7-35 [14]. The construct validity of this instrument was supported by a high Person correlation (0.88) between the SSCQ and the original Sense of Competence Questionnaire [15] as well as a high reliability (Cronbach's alpha of .89 [16]). The Pearlin Mastery Scale (PMS) evaluates feelings of mastery, consists of seven items, and a total scores range from 0-28 [17]. Previous studies reported good psychometric properties of the PMS [18-20].

Secondary outcomes

Secondarily, depressive symptoms, perceived stress, and anxiety symptoms were measured using standardized questionnaires. Depressive symptoms were evaluated with the Center for Epidemiological Studies Depression Scale (CES-D) consisting of 20 items and a total score range from 0-60 [21]. The CES-D is widely used and has good psychometric properties as shown by previous research [22-24]. The Perceived Stress Scale (PSS) includes 10 items, has a total score range from 0-40, and was used to assess perceived stress in carers [25]. A review of previous PSS studies confirmed good psychometric properties of the PSS, particularly in the 10-item version used in the present study [26]. Finally, the seven-item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) with a total range from 0-21 was chosen to rate the severity of anxiety symptoms [27]. The psychometric properties of the HADS-A have been found to be good in older adults [28].

Statistical analysis

Statistical analyses were conducted using IBM SPSS Statistics Version 24. The data-set was checked for missing values, normality and outliers before further analysis. Potential baseline differences between the three treatment groups were tested with t-tests for continuous variables and $\chi 2$-tests for categorical variables. In case of unmet assumptions, non-parametric tests were used. Baseline characteristics were added as potential confounders in the analyses in case of significant group differences.

For the main analyses, generalized estimated equation for the Gaussian family and identity-link function were specified to yield population-average unstandardized regression-coefficient (B) and their 95% confidence intervals (CI). To evaluate the impact of treatment allocation on the course of carer sense of competence, mastery, depressive symptoms, perceived stress and anxiety symptoms, treatment allocation (experimental, pseudo-experimental, control group) was entered as a between-subject factor, time (baseline, post-intervention, two-months and six-month follow-up) as a within-subject factor, and their two-way interaction as 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 α set at 0.05.

Results

Participants and descriptive statistics

A total of 76 carers participated in the intervention and 61 participants completed the two-month follow-up assessment. Another eleven participants dropped out leaving a total of n=50 carers six months after the intervention (experimental group n=17, pseudo-experimental group n=17, control group n=16). Reasons for the drop-out are listed in the flow-chart (Figure 3). There were no significant differences in the socio-demographics between the groups at baseline (Table 1).

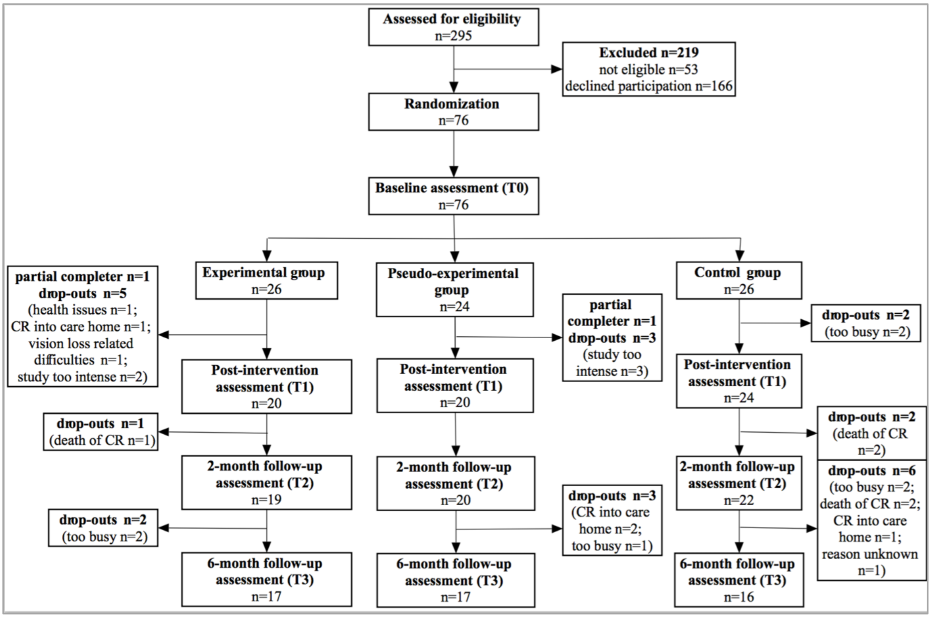

Figure 3. Flow-chart of study participation (CR=care recipient)

Primary outcomes

Sense of Competence (SSCQ). Multilevel regression analyses showed a significant overall interaction effect between treatment allocation and time on retrospectively measured sense of competence ($F(6,50)=3.329$, $p=0.007$), indicating that SSCQ scores differed between the three groups over the course of the study.

At six-month follow-up, no significant differences were found for the SSCQ score between the control group and either the experimental (B = -0.40, 95% Cl = -3.27 - 2.47, p=0.781) or pseudo-experimental group (B = -0.47, 95% Cl = -3.34 - 2.41, p=0.746). Consequently, the SSCQ scores between the experimental and pseudo-experimental group did not differ significantly six-months post intervention (B = -0.067, 95% Cl = -2.95 - 2.81, p= 0.963) (see Figure 4).

Table 1. Baseline characteristics.

	Total (n=76)	Experimental (n=26)	Pseudo-experimental (n=24)	Control (n=26)
Age, mean ± SD	72.1 ± 8.4	71.7 ± 8.4	71.1 ± 7.3	73.2 ± 9.4
Gender, n (%)				
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 (%)				
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)
Care recipient severity of dementia (CDN), n (%)				
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)
Primary Outcomes				
SSCQ; Sense of competence	25.2 (5.2)	26.1 (4.8)	24.8 (5.4)	24.7 (5.5)
PMS; Mastery	16.7 (5.7)	17.2 (6.8)	15.8 (5.1)	16.9 (5.1)
Secondary Outcomes				
CES-D; Depressive Symptoms	13.9 (8.9)	13.0 (9.8)	14.2 (8.5)	14.4 (8.7)
PSS; Perceived Stress	14.9 (6.5)	14.3 (7.8)	14.9 (5.1)	15.6 (6.3)
HADS-A; Anxiety Symptoms	6.5 (4.0)	5.9 (4.2)	6.5 (3.9)	7.0 (4.1)

No significant differences between groups in all socio-demographics at baseline. For more details, see (8).

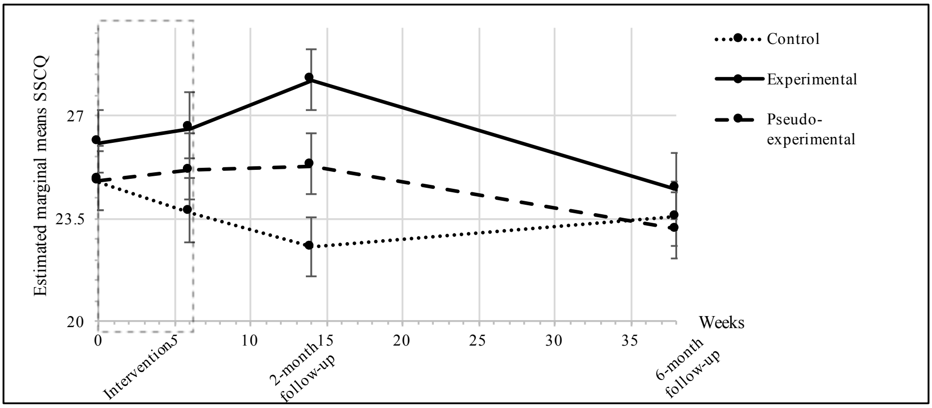

*Figure 4. Estimated marginal means of sense of competence (SSCQ). *p<0.05, **p<0.01*

Mastery (PMS) . For the PMS scores, analyses showed no significant overall interaction effect between treatment allocation and time on retrospectively measured mastery in carers ($F(6,50)=0.744$, $p=0.617$), indicating that no significant group differences were present over the course of the study.

Secondary outcomes

Perceived Stress (PSS). The overall interaction effect between treatment allocation and time on retrospectively measured PSS scores was significant ($F(6,50)=2.96$, $p=0.013$), indicating different perception of stress between the three groups over the course of the study.

At six-month follow-up, no significant difference between the groups was observed (control vs. experimental group ($B = 0.476$, 95% Cl = -4.24 - 5.19, $p=0.841$); control vs. pseudo-experimental group ($B = 0.522$, 95% Cl = -4.22 - 5.26, $p=0.826$); experimental vs. pseudo-experimental group ($B = 0.046$, 95% Cl = -4.69 - 4.79, $p=0.984$) (see Figure 5).

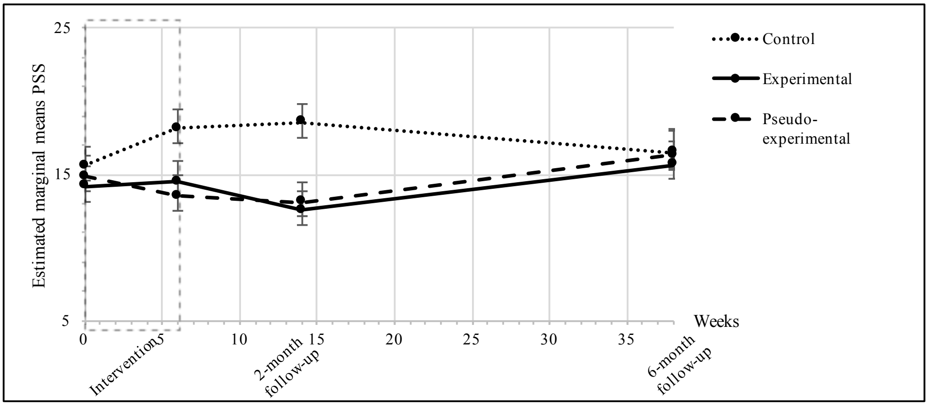

Figure 5. Estimated marginal means of perceived stress (PSS). p<0.05, p**<0.01*

Depressive Symptoms (CES-D). Analyses showed a significant overall interaction effect between treatment allocation and time on the retrospectively measure of depressive symptoms ($F(6,50)=2.553$, $p=0.028$), indicating that CES-D scores differed between the three groups over the course of the study.

At six-month follow-up, no significant results were found between groups with regards to depressive symptoms measured with the CES-D (control vs. experimental group ($B = 5.05$, 95% Cl = -0.106 - 10.21, $p=0.055$); control vs. pseudo-experimental group ($B = 2.64$, 95% Cl = -2.52 - 7.81, $p=0.309$); experimental vs. pseudo-experimental group ($B = -2.41$, 95% Cl = -7.53 - 2.72, $p=0.35$) (see Figure 6).

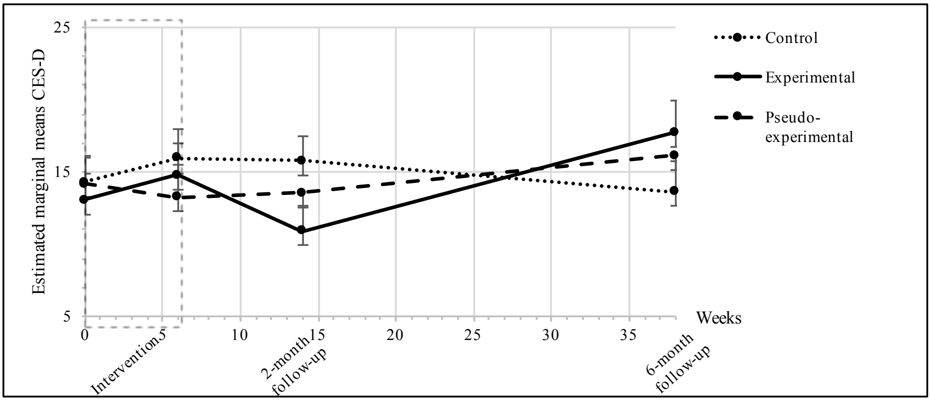

*Figure 6. Estimated marginal means of depressive symptoms (CES-D). *p<0.05*

Symptoms of Anxiety (HADS-A). The overall interaction effect between treatment allocation and time on retrospectively measured symptoms of anxiety measured with the HADS-A was non-significant (F(6,50)=1.65, p=0.15), indicating that no significant group differences were present over the course of the study.

Details of the results of all outcome measures directly and two-month post-intervention can be reviewed at Van Knippenberg et al. (2018) [8].

Discussion

This study examined the sustainability of effects after six months of a promising six-week-long ESM intervention for informal carers of PwD. The outcome measures evaluated carers' well-being namely sense of competence, feelings of mastery and psychological complaints (depressive symptoms, anxiety and perceived stress). While the results obtained after two months showed that the intervention 'Partner in Sight' can reduce feelings of stress and depressive symptoms as well as enhance sense of competence in carers [8], no positive effects could be reported after six months. As the study design was orientated on the design of an ESM intervention for depressed outpatient with sustained intervention effects over six months [9], the disappearance of beneficial effect in the present study was unexpected. The 'Partner in Sight' intervention was theoretically based on the idea that self-monitoring, particularly in combination with a personalized feedback, would promote an emotional and behavioural change towards more enjoyable activities [29]. Carers would thus become more aware of and engage more in behaviours that elicit positive emotions, such as relaxation and social activities. The coping process model suggesting furthermore that positive emotions are important to cope with challenging life events [30, 31], such as caring for a person with dementia. Additionally, the broaden-and-build theory believes that positive emotions build a person's resources [32, 33], potentially influencing feelings of mastery, sense of competence and emotional well-being [34, 35]. As the 2-month follow-up results showed [8], this theoretical basis was widely constructive. However, in carers of PwD the intervention design might have been lacking additional features to sustain beneficial effects on well-being.

Noticeable is the fact that this ESM intervention is not the only psychosocial intervention in dementia care not finding sustainable intervention effects after a few months, as a similar disappearance of positive effects over time has been observed in other studies. For example, providing a comprehensive home care program for people with early stages of Alzheimer's disease and their carers reduced feelings of burden in carers six months after the intervention started but not at 10, 14 or 18 months [36]. Similarly, carers' coping strategies improved after three months participating together with the care recipient in the Meeting Centers Support Program. The post-measure at seven months revealed the disappearance of this positive intervention effect [37]. A short telephone-based cognitive behavioural intervention for carers leading to positive long-term effects on one scale for emotional well-being with small effect size[38]. In the same study, no significant group differences were found for depressive symptoms, health status, bodily complaints and quality of life after two years [38]. These studies are but some examples and due to the difficulty to publish negative results [39], it is possible that a variety of psychosocial interventions experienced the disappearance of positive intervention effects but did not publish these findings.

In general, the goal of systematic reviews focusing on psychosocial intervention in dementia care seems to be the evaluation of their composition and effectiveness rather than the sustainability of these effects [6, 40]. Pinquart and Soerensen [41] observed that the effect-sizes of carer interventions are usually small and fewer significant effects appear at follow-up. Reviews further reveal that most studies (60-90%) did not follow up participants at all or report effects only during a relatively short period of less than six months post-intervention [7, 42-45]. Where interventions include additional follow-ups, there is a considerable variation in the length of follow-up amongst trials [46, 47], leading to difficulties in comparison between studies. Finally, the number of studies using identical instruments and follow-up measurement points in similar target groups is limited [48, 49]. An example of another intervention for carers of people with dementia that effectively increased well-being over the intervention period but treatment effects were not maintained after six months is the internet-delivered cognitive-behavioural intervention called Tele.TAnDem [50].

In the present study, the recession of positive intervention effects could be ascribed to the following aspects. To start with, the intensity of the intervention may have been too low. A high intervention intensity is generally associated with greater long-term effects [51]. The design of the present intervention was based on the setup originally aimed at depressed outpatients with a similar six-week intervention period. However, it provided twice the amount of feedback sessions [9]. The results showed a sustainable reduction of depressive symptoms six months post-intervention. The decision to reduce the feedback sessions in our study was made in order to avoid potential overburdening of carers as both the caring-tasks and the ESM intervention require time. Future research could pay extra attention to adjusting the balance between both.

Furthermore, the theoretical framework of the intervention was originally built for depressed outpatients, for whom positive affect is an important drive [52]. Raising awareness for positive affect in people with depression can lead to actual behavioural changes and thereby long-lasting effects [53]. In carers, this framework might need adjustment as caring for a person with dementia is a complex task not only accompanied by depressive symptoms but other stressors. This interesting research question focusing on carers' behavioural change in everyday life will be addressed shortly. Outcomes of interventions are influenced by a variety of features such as the context, individual participant responses to and interactions with the intervention, other mediators and unexpected pathways and consequences [54] and therefore, insight into causations are essential.

Generally, the 'Partner in Sight' intervention might be beneficial to improve carers' well-being over a certain period of time but adjustments to meet the altered needs of carers over time [55] could contribute to sustain effects. Furthermore, after the 'Partner in Sight' intervention, carers in the experimental group showed a non-significant increase of depressive symptoms between the 2-month and 6-month follow-up (see figure 5). This trend may again highlight the need for an intervention design to provide support long-term as not having access to an intervention that initially provided relief might later aggravate the well-being of the carer.

The trend could also be explained by a deterioration of the care recipients condition, or a combination of both. Dementia as a progressive neurodegenerative disease leads to continuous changes and a range of new challenges for the carer. Therefore, a stabilization of carers' well-being rather than decline can already be seen as a positive outcome.

There are general limitations to this study. First of all, the study is likely to be underpowered to detect smaller intervention effects in the long-term as the recruitment itself was a challenge resulting in a small sample size at baseline. Over the course of the study, the rate of drop-outs due to care recipients moving into care homes, death of care recipients or a high load of carers' obligations led additionally to a selective attrition and reduced participation at six-month follow-up. Additionally, the composition of the study population might have influenced the outcome resulting in questionable generalization. As mentioned above, ESM interventions are time-consuming, potentially resulting in an initial selection bias towards a group of carers not yet exposed to the high demand of care. Furthermore, the feedback sessions were originally planned to have a duration of 45 minutes, but lasted in the experimental group (~90 min.) significantly longer than in the pseudo-experimental group (~60 min.). This difference in personal contact with the coach could have influenced the results. Finally, other factors such as the financial status or holistic living situation (i.e. not only living with the person with dementia but also other family members) were not taken into account and might have potentially influenced the intervention effects.

Recommendations to Achieve Sustainability of Intervention Effects

Carers of PwD expressed the need for support provided over a longer period [56]. Clinicians and researchers should be aware of this need and aim to meet it. Thus, interventions for carers should include additional features after the main period of the intervention.

Examples to report on sustainable intervention effects in dementia care are the studies by Livingston et al. (2014) and Mittelman et al. (2004) [57, 58]. Livingston et al. (2014) conducted eight sessions of a manual-based coping intervention improving carers' depression and anxiety sustainably over two years. However, their study is the only one finding long-term results without any additional features after the intervention period and underlying mechanisms are not evaluated [57]. In contrast, Mittelman et al. (2004) added additional features after the main period of the intervention. Initially, carers were randomly assigned to either a group receiving enhanced counselling and support treatment, or a control group, receiving usual care. The treatment group participated in six sessions of individual and family counselling. After the main intervention, the attendance of support groups four months after enrolment and ongoing ad-hoc counselling resulted in a decrease of depressive symptoms in the treatment group compared to the control group over a period of 3.1 years post-enrolment. Consequently, a short intervention, counselling and readily available supportive maintenance can have long-lasting effects in reducing symptoms of depression among carers of PwD [58].

Availability of Experts/Counsellors

In the ‘Partner in Sight’ intervention, counselling took place during the feedback sessions. Prospectively, if the intervention would be delivered via the PsyMate application rather than the mobile device, ongoing contact with an expert could be promoted. A messaging function is not yet integrated in this particular application but other smartphone applications offer chat options and mHealth interventions would be generally able to maintain contact after the intervention. The availability of a counsellor at any time after the intervention eventually gives carers a feeling of security when facing problems and the chance to adapt to new challenges with encouragement.

Flexible Tailoring to Change in Needs

Most interventions follow a personalized approach. Researchers and clinicians should be aware, however, that a person-tailored intervention might need to be adapted along the course as the context and the needs of the carer might change [55]. The framework by Chiu & Eysenbach (2010) highlighted the importance for eHealth interventions to be dynamic, continuous and longitudinal with respect to the different stages of the dementia [59]. Regular evaluation of the expectations and suggestions from the carers could help to optimize the support. In the ‘Partner in Sight’ intervention, the ESM itself was incorporated in everyday life. Furthermore, the individualized feedback for each carer ensured flexibility and tailoring. This procedure should not be limited to the intervention period only. Potentially, the PsyMate application could be used by the carer autonomously with an online feedback and the option to contact the clinician if needed. Thus, self-monitoring and self-management could be promoted and might give the carer insight into changes in own emotions and behaviour.

Booster sessions

Interventions in dementia care might need regular booster sessions post-intervention to guarantee a long-term effect as incorporated in a drug abuse prevention program [60]. Through such a booster session, the participant might be reminded of learned strategies or knowledge achieved during the intervention. In carers especially, it might raise awareness for own strengths and offers opportunities to adapt these strengths to other contexts in everyday life. Booster sessions in an ESM intervention could mean a micro-intervention of a few days a couple of months after the main intervention including a personalized face-to-face or digitalized feedback.

Implications

In the last years, e- and mHealth strategies have been increasingly used in clinical populations not limited to dementia care to improve individuals’ well-being and health, to promote the communication between professionals and health care recipients, and reduce costs of health care [61, 62]. The evaluation of the effectiveness and efficacy of mHealth interventions seems promising [63, 64], even though, the sustainability of mHealth intervention effects needs more attention. The underlying mechanisms to achieve these sustainable intervention effects for carers of PwD, however, are currently unknown. Qualitative research could evaluate carers' ideas on this topic via interviews or focus groups.

E- and mHealth interventions delivered by a mobile device or application offer the unique opportunity to provide a flexible, personal-tailored approach with a 24/7 access to experts. The present study can be seen as the first step towards a sustainable support for carers. Future research might focus on features such as notifications in apps, regular emails or reminders in mobile devices to promote booster effects. Additionally, research on programming technology tailored to personal needs, including education and coping-strategies would be beneficial. Most importantly, the option to share questions and problems with the social network including family, friends, and clinical experts at any time should be investigated. With increasing awareness for the necessity for support throughout the carers' entire career, we hope to be able to assist carers optimally in caring for their loved ones living with dementia.

Conclusion

The 'Partner in Sight' experience sampling intervention had beneficial effects on carer's well-being over a period of two months, however, not six months. Reflecting on this result as well as outcomes of other interventions, it is suggested to prospectively include additional features such as ad-hoc counselling options and booster sessions as well as ensure flexible adjustment to meet the changing needs of carers. The caregiving career continues often over years and therefore, clinicians and researchers need to be aware of the necessity for sustainable intervention effects.

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Appendices

Appendix 1. Description of the ESM 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 of 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')

Appendix 1. Continued.

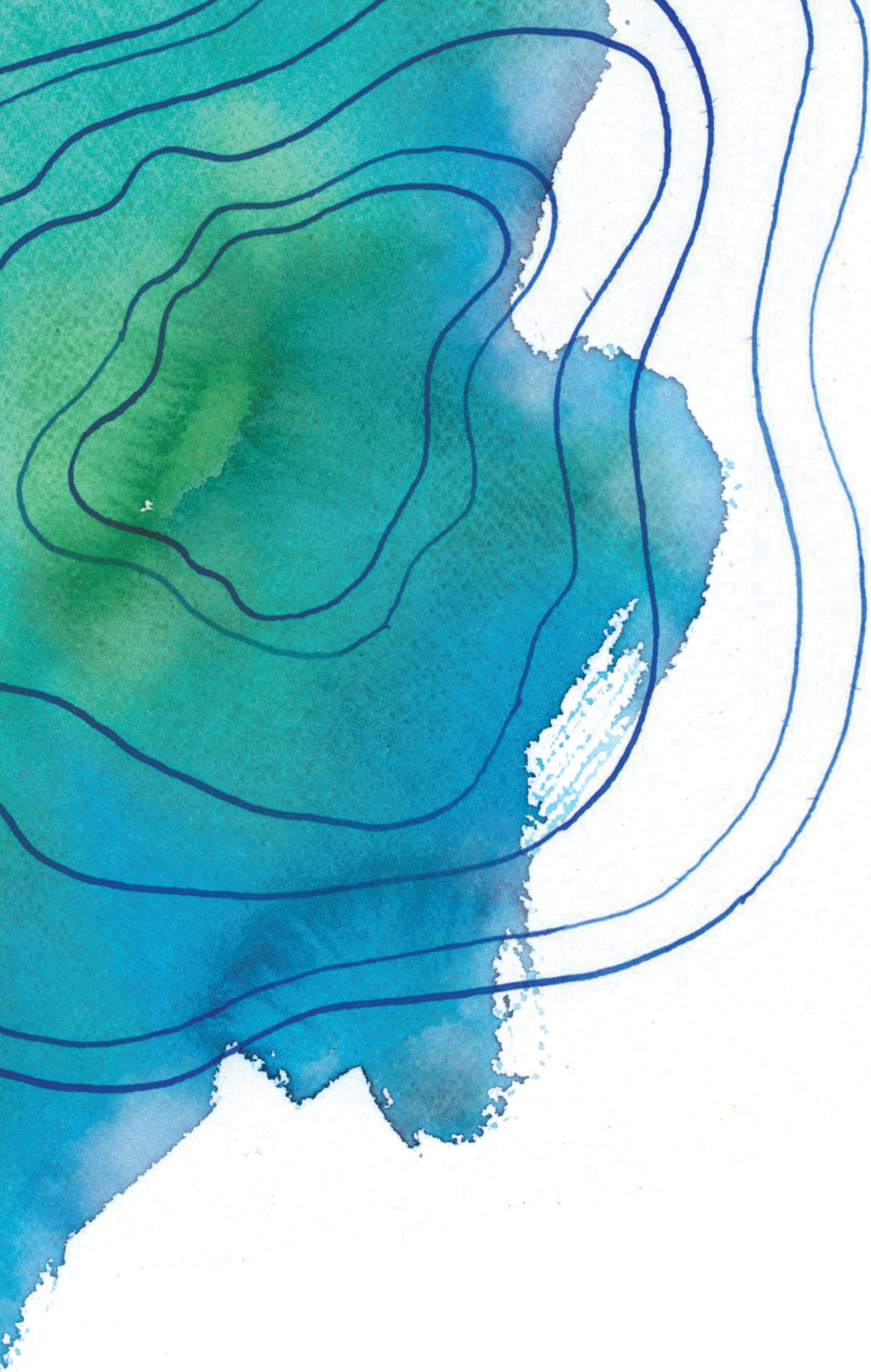
Daily questionnaire		
Concept	**Item**	**Rating scale**
	29. I am doing this activity together with my partner	Yes; no
Location	30. Where am I?	At home; at family's/friend's place; at work; health care setting; public place; transport; somewhere else
Social company	31. Who am I with?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	32. With whom else?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	33. And…?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	Branching questions in case of being in company:	
	34. I would prefer to be alone	7-point scale (1 'not at all' to 7 'very much')
	35. I think my company is pleasant	7-point scale (1 'not at all' to 7 'very much')
	36. I feel at ease in this company	7-point scale (1 'not at all' to 7 'very much')
	Branching questions in case of being alone:	
	34. I would prefer to be in company 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')

Appendix 1. Continued.

Morning questionnaire		
Concept	**Item**	**Rating scale**
	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')
	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	7-point scale (1 'not at all' to 7 'very much')
	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')

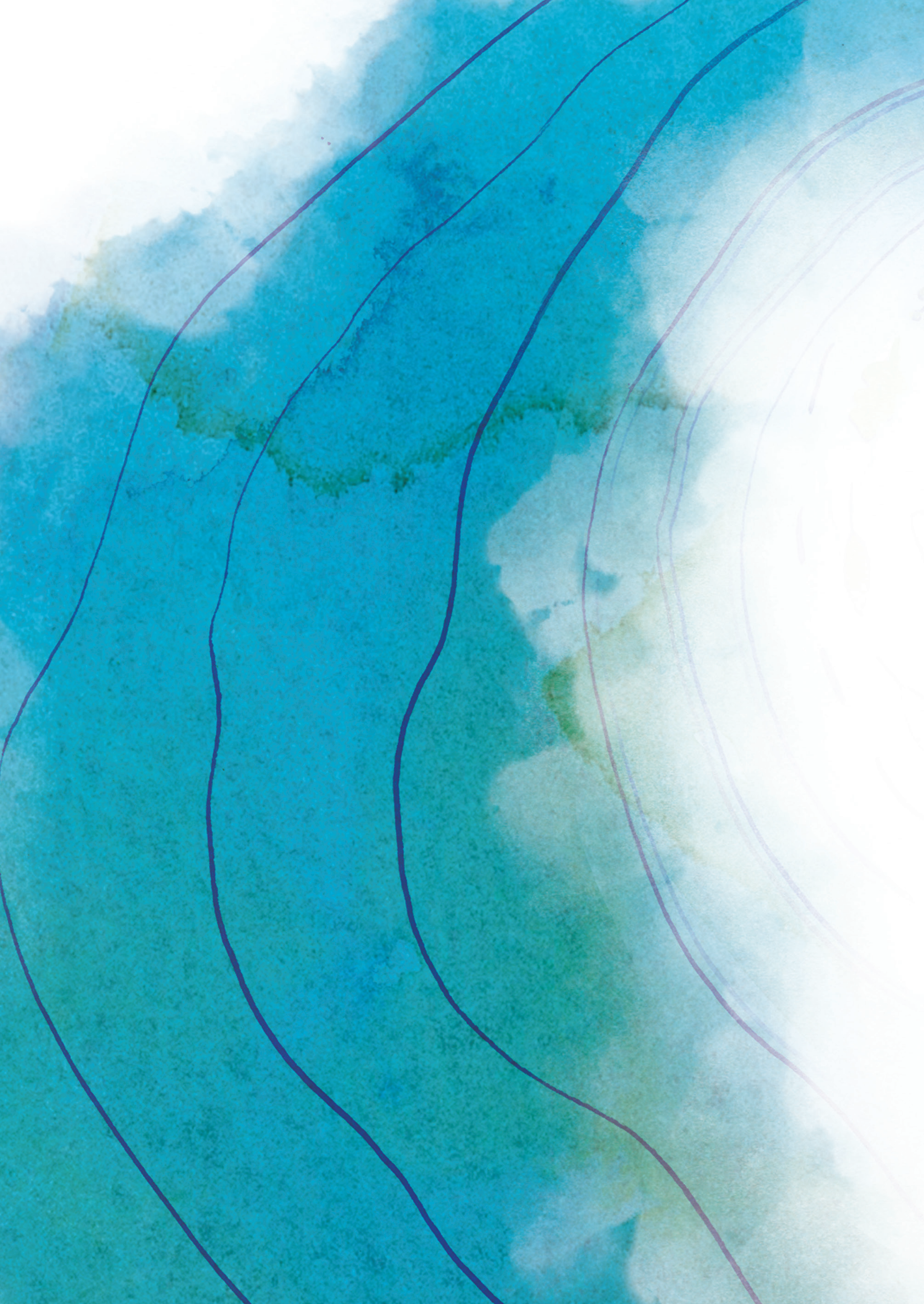
Appendix 1. Continued.

Evening questionnaire		
Concept	**Item**	**Rating scale**
	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')



Part III

Implementation



Chapter 9

A Systematic Review on the Implementation of eHealth interventions for Informal Caregivers of People with Dementia

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Abstract

Objectives: The objectives were to (1) systematically review the literature on the implementation of eHealth interventions for informal caregivers of people with dementia, and (2) identify determinants of successful implementation.

Methods: Online databases were searched for articles about eHealth interventions for informal caregivers of people with dementia, providing information on their implementation. Articles were independently screened and inductively analysed using qualitative analysis. The analysis was mapped onto the Consolidated Framework for Implementation Research (CFIR [1]).

Findings: 46 articles containing 204 statements on implementation were included. The statements on implementation were grouped into four categories: Determinants associated with the eHealth application, informal caregiver, implementing organization, or wider context. Mapping of the determinants on the CFIR revealed that studies have focused mostly on characteristics of the intervention and informal caregiver. Limited attention has been paid to organizational determinants and the wider context.

Conclusions: Despite prolific effectiveness and efficacy research on eHealth interventions for caregivers of people with dementia, there is a critical dearth of implementation research. Furthermore, there is a mismatch between eHealth intervention research and implementation frameworks, especially concerning organizational factors and wider context. This review underscores the importance of future implementation research in bridging the gap between research and practice.

Introduction

Informal caregivers are essential to providing home-based care for people with dementia. Research has shown that the quality of care received by a person with dementia positively relates to a longer time spent being cared for at home, which is critical to the physical and mental health of the person with dementia [2, 3]. However, informal caregivers of people with dementia often experience significant physical and psychological problems themselves as a result of this caregiving process, including increases in depression, stress, social isolation, financial burden, and disturbed sleep [4].

Given these adverse consequences, it is crucial to provide caregivers with tools to help them receive caregiving support, as well as to allow them a life outside of caregiving. With the dementia population (47 million people worldwide) expected to grow threefold by 2050 [5], this increasing need for support has led to many innovative approaches, including those emerging from the promising field of eHealth research. The term 'eHealth' describes "the use of information and communication technologies (ICT) for health" [6]. eHealth interventions are "treatments, typically behaviorally based, that are operationalized and transformed for delivery via the Internet" [7]. For instance, eHealth interventions can take the form of an online course, administered via computer; they can also be smartphone or tablet applications designed to provide psychological support from peers and professionals alike. eHealth interventions have the advantage of a lower threshold of access for participation, as well as the ability to reach more isolated populations who struggle to access traditional services [8]. Recent reviews have shown that eHealth interventions for informal caregivers of people with dementia are effective in improving a range of psychological outcomes in caregivers, such as the reduction of caregiver depression, anxiety, stress and burden, as well as increasing positive aspects of caregiving, caregiver self-efficacy, and confidence [9-14].

However, despite this proven efficacy, little is known about how to ensure that these interventions are successfully implemented (i.e. put into practice). Previous research on eHealth interventions has shown that, despite their proven efficacy, as well as enthusiasm regarding eHealth from funding and policy institutions, the implementation of eHealth interventions in ageing populations has proven difficult. Reasons for this include older individuals' changes in their perceptual, cognitive, and motor abilities, in combination with the continuing rapid development of new technologies [15]. The objectives of this review are (1) to explore the evidence on the topic of implementing eHealth interventions for informal caregivers of people with dementia, and (2) to identify determinants that influenced whether the intervention was successfully implemented. The results of this study will help bridge the gap between our knowledge of the efficacy of eHealth interventions for informal caregivers of people with dementia, and the translation of this knowledge into practice.

Methods

Search strategy

A systematic literature search of bibliographic databases PubMed, CINAHL, PsycINFO, Cochrane Library and Web of Science was conducted in May 2017. The search was aimed at finding articles that contained information on which factors determined the implementation of eHealth interventions for caregivers of people with dementia. In order to accomplish this, the aforementioned databases were searched for articles that contained terms related to all three of the following main concepts: 'dementia', 'eHealth' and 'caregivers'. Relevant MeSH and Thesaurus terms were used, as well as additional non-MeSH terms, so as to identify the full range of indexed and non-indexed articles. Appendix A details the employed search strategies: first the union ('OR') of terms to capture articles related to each single main concept, and second the intersection ('AND') of main concepts to focus on the purpose of this review.

The search strategy does not contain relevant terms related to 'implementation' (such as 'facilitators and barriers', 'determinants' or 'implementation'), because the authors anticipated that such terms are often not mentioned in the title and/or abstract. Instead, implementation issues may only be discussed in the body of the text, potentially using different terms. This information could only be assessed by reading the full-texts in a later, post-abstract screening phase. Thus, we aimed to have a complete overview of all research on implementing eHealth interventions for caregivers of people with dementia, without missing important information due to terminology constraints.

Study selection

Titles and abstracts of the identified citations were imported into Endnote, deduplicated and independently evaluated by first reviewer (HLC) and second reviewer (SLB). Included references had to involve an (1) eHealth (2) intervention for (3) informal caregivers of people with dementia and (4) provide information on its implementation. In order to assess whether references met criterion 4 (provides information on implementation), the full-texts were scanned for the presence of determinants of implementation. These were statements about factors that either facilitated or impeded the process.

Non-intervention studies such as reviews, trial protocols, book reviews and consensus papers were excluded. Otherwise, any design was judged as suitable for inclusion. Studies on assistive technology that were not specifically designed to improve caregiver well-being, as well as telephone-only, video-only and CD-ROM-based interventions were also not included. Non-English-language publications and articles published before 2007 were excluded from this review. 2007 was chosen as the cut-off year for this review. It was believed that studies from more than 10 years ago would not provide much additional, relevant information due to the evaluated technologies having become outdated, as well as policies and organizations having changed greatly in the interim. After searching for eHealth "All Fields", the PubMed-generated histogram 'Results by year' showed a rise in eHealth research after 1994, followed by a plateau from 1998 to 2007. After 2007, the number of references recommenced its rise. The authors concluded that 2007, the year of the first iPhone, signified a turning point in mobile technology [16] and a relevant cut-off point. Any disagreements about inclusion were resolved through a consensus meeting consisting of three reviewers; HLC, SLB and MEdV.

Data extraction

Articles that met all four criteria were compiled into a standardized data extraction instrument as recommended by Cochrane Handbook for Systematic Reviews of Interventions [17] (see Appendix B) detailing primary study characteristics (author/year, design, setting, study population, intervention, measures, findings and country of study), as well as the extracted determinants. The PRISMA guidelines [18] were used to guide the process of study selection and data analysis. However, not all elements of this guideline were followed as this systematic review focused on process characteristics and not on effectiveness.

Data analysis

A qualitative thematic analysis was performed in which statements related to eHealth implementation ("the process of putting the intervention into practice") issues were coded and labeled 'determinants'. The determinants were inductively grouped to form thematically similar categories, subcategories and groups. The authors opted for an inductive method in order to best scope the available literature and contrast the findings with existing implementation frameworks. Reviewers HLC and SLB independently coded and mapped these determinants by hand, identifying the article as 0 (contains no determinants) or 1 (contains determinants) and mapping these determinants into inductive categories using an online 'mind mapping' tool (Google Mindmup 2 software, October 2017 version, developed by Sauf Pompiers Ltd.; https://drive.mindmup.com). In the next step a consensus meeting was held between reviewers HLC and SLB, with the input of reviewer MEdV. Finally, to structure and contextualize the findings, the resulting analysis was compared and mapped onto the Consolidated Framework for Implementation Research [19]. The Consolidated Framework for Implementation Research (CFIR) was chosen because it is a commonly used, practical set of constructs, which were readily applicable to eHealth intervention research for caregivers of people with dementia.

Results

Figure 1 depicts a flow chart illustrating the process of inclusion and exclusion. The search strategy described in Appendix A resulted in a total of 2524 records after deduplication. 2401 articles were excluded because they did not meet the criteria of involving an (1) eHealth (2) intervention for (3) informal caregivers of people with dementia. After screening these full texts for the fourth criterion ("provides information on implementation"), 46 records were included, which contained 204 determinants of implementation. `

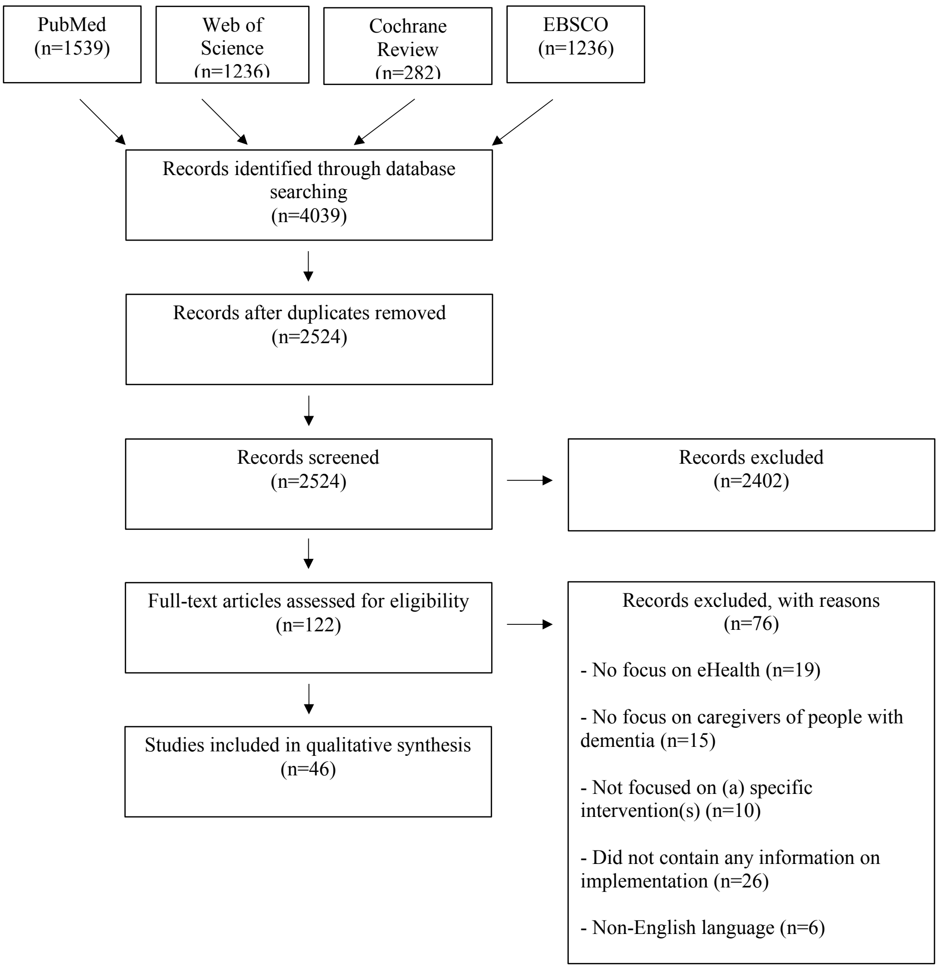

Figure 1. Flow chart of process of inclusion and exclusion

The results of this search strategy show that only two of the included 46 references were implementation studies [20, 21]. The results of this search strategy show that only one of the included 46 references used the term 'implementation' in the title [22] and one study used the term 'process evaluation' in the title [23]. Four more studies were designed as retrospective evaluations of barriers and facilitators to the development and implementation of eHealth interventions for caregivers of people with dementia [24-27]. The included papers could be classified by type of study as RCTs (n=16), pre-test and post-test mixed methods studies (n=15), qualitative analyses of interviews and other text-based sources (n=14), and quantitative studies, like questionnaires (n=2). When classifying the references by type of intervention, the vast majority of the included interventions concerned web-based platforms for psycho-education and support (n=38). The remaining interventions (n=9) were adaptations of existing in-person psychosocial interventions to technological platforms including individual videophone, group and individual teleconference, and group virtual reality sessions. For a more detailed overview of the types of included interventions, see the Extraction Table included in Appendix B. The determinants have been grouped together inductively in four thematic categories, namely 'Determinants associated with the eHealth application', 'Determinants associated with the informal caregiver', 'Determinants associated with the implementing organization' and 'Determinants associated with the wider context'. In the following sections the main findings are presented. Table 1 is an overview of the thematic categories and subcategories.

Determinants associated with the characteristics of the eHealth application

The largest thematic category of determinants was 'Characteristics of the eHealth application': 116 of the 204 determinants fell into this category. A large group of the determinants in this category described ways of facilitating the implementation process by making the eHealth application itself more user-friendly. For instance, application developers must make hyperlinks to navigate through the application easily identifiable and consistent. In terms of the development process of the interventions, the importance of user-involvement throughout the whole process and allowing for enough time to improve the website were recurrently identified as important facilitating factors.

Table 1. Overview of themes, categories and subcategories, with references

Theme 1:Determinants associated with the eHealth application		Theme 2: Determinants associated with the informal caregiver	
Categories and Subcategories	References	Categories and subcategories	References
User-friendliness	22,23,28-38	Psychological factors	
Development Process	39-42	*Expectation of use*	36,41
Features of the intervention		*Psychological state*	22,58,62,63
Suggested	23,32,36,37,39,43,44	*Trust*	27
improvements	36,40,45,32,36,46,47	*Autonomy*	64
Link to social media	37,48,49	*Motivation*	34,36,39
Embodied experience	37,50	*Confidence*	64
Security	51	*Frustration*	22,42,56
Importance of personal contact	49,51-53	*Cyber rapport*	22,56
Simplicity		*Privacy*	25,34,54,57
Importance of	23,24,32,40,46,54,	Knowledge	
simplicity	55,27,32,36,56,57	*Digital literacy*	23,24,40,48,54,59,64,65
Security problems with complexity	51,52	*Mental health literacy*	24,27,54
Simple language	24,30,37,38,45,58	*Learning*	24,34
Information dosage	27,34,40,45,	Demographic variables	
All information in one place	30,32	*Education*	44,58,63
Compatibility		*Ethnicity and culture*	30 58,66
Convenience of home	45,57,59	*Gender*	46,58
Time	54,55,60	*Age*	26,58,63
Cost	32,48	Participation	
Trial factors		*Reasons to withdraw*	22,34,41
Recruitment	40,41,52,59,61	*Reasons to participate*	64,67
Outcomes	32,45,47	Relation to person with dementia	
Adaptability	26,27,29,32,34,42, 45,49,54	*Dementia diagnosis*	40,63
		Relationship	46,58,63
		Workload	27,58,68
		Social Support	69
		Regular usage	54

Table 1. Continued

Theme 3: Determinants associated with the implementing organisation		Theme 4: Determinants associated with the wider context	
Categories and Subcategories	References	Categories and subcategories	References
Staff factors		Care policy	48,66,67
Lack of staff	40	Country-specific problems	29,42,61,67
Lack of staff interaction	56	Ethics	
Staff training	44	*Informed consent*	57
Staff replacement	48	*Equal access*	57,61
Types of support	30,36,41,42,54,64,70		
Staff attitudes	42,64		
Financial factors			
Funding	40,48		
Face-to-face	23		
Profit	48		
Time available			
Trial period too short	36,39-41,57,60		
Planning	41		
Organisational factors			
Provider collaboration	48,49,64		
Size of organisation	48		
Teamwork	42		
Integration	48,54,56,61,62,64		
Strategies	27,64,71		

Additionally, the included articles listed many ‘lessons learned’ and a great number of determinants described ways in which the features of the applications could be optimized. First, several determinants specified additional features. A frequently mentioned request from participants was for the addition of a ‘search function’ to the platform. Next, many determinants stressed the importance of appropriate content: The determinants suggested that the content should take into account the phase of dementia and preferred themes of instruction, and that the developers must also invest in keeping the content up-to-date. Another important feature of an application is its link to social media: The included articles contained several determinants describing the positive effects of social media on the intervention’s content and reach. Additionally, one study determined that ‘embodied experience’ was important for online engagement, and several studies stressed how applications must take appropriate measures to include the maximum amount of security.

For instance, several determinants mentioned that continuous troubleshooting support was essential and that participants experienced concern about a lack of security as a significant barrier. Finally, many determinants proposed that a sense of adaptability and personal contact is what made the intervention effective.

Simplicity was a recurring subject of many implementation determinants. Application users stressed the importance of reducing the amount, spread and complexity of information, adding that complexity is associated with increased security risks. They also preferred the language used to be as simple as possible. Compatibility was another common theme, where determinants described the convenience of the at-home setting of eHealth interventions, the effect of time on both the emergence of effects, as well as on the changing needs of the users and the cost. A large number of determinants described the effect of the trial setting on the interventions and the implementation difficulties these restrictions caused. Finally, human interaction with application featured strongly in the literature, most noticeably in how the participants wanted their application to be adaptable and personalized to their needs.

Determinants associated with the informal caregiver

The second largest thematic category was 'Determinants associated with the informal caregiver'. Sixty-nine of the 204 determinants fell in this category. Many implementation determinants described certain psychological characteristics of the informal caregiver that facilitated or impeded implementation. These characteristics included the caregiver's expectation of use, their psychological state (though studies reported both positive and negative effects of higher burden on engagement with the intervention), trust, autonomy, motivation, confidence, frustration, cyber rapport and privacy. Of note is that the largest group is 'Privacy', with statements emphasizing the anxiety often felt by participants about using technology to document personal issues, and the need to address this barrier.

Another factor that determined an intervention's success in being translated into practice was the informal caregiver's knowledge. For instance, (especially a lack of) digital literacy and mental health literacy, as well as the caregivers' learning styles, were mentioned as determinants by the included studies. Moreover, certain demographic variables such as gender and age were identified as implementation determinants. In particular, ethnicity and culture were frequently mentioned, with determinants suggesting that interventions could have minority specific effects. Interestingly, education was not described as having a large impact. The informal caregiver's relation to the person with dementia was seen as important. For example, increased severity of the dementia diagnosis was a barrier, though the presence of a formal diagnosis was seen as beneficial. Additionally, the type of relationship to the person with dementia (spouse, child, neighbor, etc.) also played a role. For instance, in one study [46] the relationship correlated with program opinion (husbands and sons were more positive about the program). Caregiving workload was also identified as an important factor, in that the busier caregivers were, the less usage took place. Finally, social support and regular usage were each reported (once) as facilitating factors.

Determinants associated with the implementing organization

This category contained 46 of the 204 determinants. Quite a few included studies mentioned determinants associated with the staff of the implementing organization. A lack of staff and a lack of interaction with staff were described as barriers to implementation. Staff training, replacement when staff leave and the presence of staff practitioners were described as facilitators. Certain staff attitudes were cast as negative determinants of implementation. Reluctance about the technology, as well as insecurities (about both ethical and technological issues) were reported as impeding implementation within the organizational context.

Many determinants focused on the barriers posed by financial and time constraints. It was reiterated that including a face-to-face element to the intervention is beneficial, though it increases costs considerably. Some studies specified certain characteristics of the implementing organization itself. For instance, five determinants stressed that researchers need an intervention "provider" to collaborate with in implementing the intervention. Determinants also stressed the importance of teamwork and highlighted that smaller organizations struggle to provide the necessary support and up-to-date content previously described, due to lack of a PR department and other necessary facilities. The articles also included determinants detailing the barriers posed by this necessary integration of the intervention into existing (care) systems. Among them are privacy issues, competition between organizations, and gatekeeping by members of the organization. Finally, suggested implementation strategies included reconciling community and organizational characteristics, streamlining processes for monitoring intervention fidelity, and active facilitation of the service uptake.

Determinants associated with the wider context

This final category is the smallest and contains 20 determinants. Care policy was described in a few articles as an important determinant of implementation. In particular, the limited capability of health insurance authorities to support innovation, and their preference for classically delivered care was identified as a significant barrier. Moreover, many municipalities do not see the added value of a disease-specific tool. However, it was also stated that an important facilitator was that eHealth and its philosophy of self-management fits within recent policy developments. A country-specific facilitator was the Affordable Care Act in the U.S.A. Country-specific barriers included the slow availability of broadband in the Netherlands, and the difficulties associated with Spanish-language websites, such as barriers with international search engines. Finally, 11 determinants also discussed certain ethical issues encountered in their study, that posed potential barriers in successfully implementing the intervention. In this regard, requirements concerning informed consent were described, as well as a number of issues pertaining to equal access. For instance, within a trial context, all users should be offered training, support, internet access, and all necessary equipment free of charge.

Mapping the determinants

The Consolidated Framework for Implementation Research (CFIR) [19] offers a framework to contextualize and structure the identified determinants. The CFIR is composed of five major domains: Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of the Individuals Involved, and Process of the Implementation. These domains each contain a number of constructs, which are not discussed in detail here [19]. The majority of the determinants (see the Extraction Table, Appendix B) identified by this review can be situated under the domain Characteristics of the Intervention and the domain Characteristics of the Individuals Involved (normally, the implementing organization; here, the informal caregivers) that used them. Very little work has been done on continuing the interventions past their trial phase [72] and evaluating factors associated with the Process, Inner Setting, and Outer Setting. Table 1 confirms that the majority of determinants provide information on how the application and user characteristics might influence successful implementation, while much less is being said about the determinants associated with the implementing organization and the wider context.

Discussion

Overview of the existing implementation research

The first objective of this study was to explore what research had been done concerning the implementation of eHealth interventions for caregivers of people with dementia given the abundance of effectiveness trials for these interventions [9-14]. The fact that only one study could be found referring to 'implementation' in its title suggests that implementation research on eHealth interventions for caregivers of people with dementia is still in its infancy [22]. Indeed, the implementation literature is dwarfed by the efficacy literature, though this is by no means specific to eHealth interventions [73].

Summary of identified determinants of implementation

Despite the paucity of specific implementation research, there were many studies that described valuable experiences and 'lessons learned' in putting interventions into practice. In relation to this study's second objective, summarizing what the literature has described as determining factors for implementation, this review has identified four main groups of determinants. This has resulted in a useful overview of the current literature for future researchers to inform the development and implementation of their eHealth interventions for caregivers of people with dementia. For instance, when it comes to designing an eHealth intervention to facilitate implementation, a number of recommendations have been made to increase user-friendliness and design features relevant to caregivers. Furthermore, it is important for applications to be flexible, personalized, and adaptable to the individual needs of the participants. Previous eHealth studies have also underscored the importance of personalization [74-77], citing the effect of the perceived increased personal relevance of the intervention. Moreover, this review provides evidence that there are a number of important factors associated with the person of the caregiver. Psychological factors, prior knowledge and learning styles, demographic variables, reasons to participate/withdraw, the relationship of the caregiver to the person with dementia, the availability of social support, and the caregivers' workload and regular usage of the intervention were all reported to influence engagement and subsequent implementation. This (in addition to the frequently mentioned prerequisite of 'personalization') suggests that there is no 'one size fits all' implementation approach to eHealth for caregivers of people with dementia. As is typical for psychological interventions, it is a matter of 'what works for whom' [78]. The fairly limited amount of studies that discussed determinants associated with the implementing organization emphasized the importance of staff factors, financial resources, time, organizational factors, and integration into existing systems, in addition to recommending a number of specific strategies. When it came to the wider context, studies stressed the effect of local care policies, as well as ethical dilemmas, that influenced implementation.

A mismatch between implementation research and eHealth research

The two largest themes of determinants were mapped onto the CFIR domains Characteristics of the Intervention and Characteristics of the Individual. There was a marked absence of studies going into depth on the CFIR domains Process, Inner Setting, and Outer Setting. This uneven distribution showcases an important finding of this review: There is a mismatch between the focus of research being conducted on eHealth interventions for caregivers of people with dementia, and the focus of implementation frameworks to guide and assess their implementation.

On the one hand, the focus of the research being conducted on eHealth interventions for caregivers of people with dementia does not match the existing implementation frameworks very well. Specifically, there are two implementation blind spots in the current literature on eHealth interventions for caregivers of people with dementia. First, there is a noticeable lack of research examining the effect of contextual factors, such as the organization and wider context. This is evidenced by the relatively few articles in the themes 'Determinants associated with the implementing organization' and 'Determinants associated with the wider context'. The absence of knowledge on the contextual environment creates significant difficulties for health system planners and implementers who aim to translate these interventions into practice [72, 79]. Indeed, Goldzweig et al. (2009) propose that, despite its many advantages, the paucity of information on contextual factors and process changes has contributed to the slow implementation of eHealth in general [80]. Second, very few studies place emphasis on the process and time-related factors. For instance, there is a need for studies discussing the iterative process of adapting both the intervention and the organization (redefining and remodeling, respectively) [81], and formatively evaluating this adaptation process. Furthermore, the included studies mostly focused on putting the interventions into practice merely in the context of academic research, with very little work being done on continuing the interventions past their trial phase. The CFIR is not alone in emphasizing the importance of these contextual and time-related factors, as these are dimensions that recur frequently in many common implementation frameworks [82-85].

On the other hand, the focus of the implementation frameworks does not match the conducted eHealth research well. Implementation frameworks struggle to encompass the wealth of information from eHealth studies at the level of the end-user (in this case, the informal caregiver). Though the second largest group of identified determinants fell under the theme 'Determinants associated with the informal caregiver', the CFIR and other implementation frameworks have little room to place these end-user determinants. While there are more psychology-related models that emphasize the perspective of the end-user [86-88], there remains a lack of suitable implementation models to map the complexity of end-users' determinants and interactions with the application. Instead, as is the case with the majority of implementation frameworks [82-85], the CFIR describes implementation from the perspective of the implementing organization: The domain 'Characteristics of the Individual' again refers to the individuals within the organization, and not the end-users (informal caregivers).

In sum, both eHealth intervention research and organizational implementation research contain gaps of understanding, and future implementation research must take an integrative and multidisciplinary approach in order to be effective. Frameworks such as the Medical Research Council's (MRC) framework for complex interventions [89] can provide guidance for eHealth solutions by placing emphasis on investigating contextual determinants and other process characteristics through process evaluations.

Limitations

This study has some limitations. First, the employed search strategy did not include methods of searching grey literature or studies that have not been written up in English. By not including these sources, we may have missed valuable information. Second, because this review's focus was on implementation characteristics, articles were not selected based on the quality of their effectiveness study. However, the included articles were sourced from peer-reviewed journals, signifying that they are all of an academic quality and level. Finally, this review draws on secondary analyses. This highlights the lack of readily available primary data on eHealth intervention implementation, illustrating the need for the collection of such implementation data in future research.

Conclusions

This review aimed to explore what is known about the implementation of eHealth interventions of caregivers of people with dementia. Its findings illustrate that little attention has been paid to their implementation in the real world, outside of the academic intervention research context. When research does mention implementation, it is often limited to the characteristics of the application and of the end-users (in this case the informal caregivers). Practical implementation issues, systematically involving organizational factors, and taking into account contextual and societal factors, have largely been neglected. Conclusions drawn from the included non-implementation research nonetheless give insight into a range of ways in which characteristics of the eHealth application, informal caregiver, implementing organization, and wider context can facilitate their successful implementation.

eHealth interventions show promise for improving the lives of informal caregivers, and reducing future strain on health care services by enabling caregivers to care longer and more ably for their loved ones with dementia. Moreover, eHealth interventions are uniquely suited for widespread implementation due to their low cost, low threshold of access, and potential for personalization to achieve tailor-made solutions. However, it is imperative that future research prioritizes implementation research and evaluates barriers and facilitators to long-term use in the community. Finally, without evidence-based knowledge of effective implementations strategies, researchers developing eHealth interventions for caregivers of people with dementia will be hard-pressed to convince the necessary stakeholders and decision makers of their practical use, and thus allow these innovative and exciting interventions to make a difference in the lives of the caregivers who would (and should) benefit from them.

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Supplementary Materials:

Appendix A. Search Strategy.

1 **PubMed**:((“telemedicine”[All Fields] OR digital[All Fields] OR (“videotape”[All Fields] OR “recording”[All Fields]) OR “videotape recording”[All Fields] OR “video”[All Fields]) OR (“telecommunications”[MeSH Terms] OR “telecommunications”[All Fields] OR “telecommunication”[All Fields]) OR telecoaching[All Fields] OR (“telecommunications”[MeSH Terms] OR “telecommunications”[All Fields] OR “teleconference”[All Fields]) OR (“telephone”[MeSH Terms] OR “telephone”[All Fields]) OR “technology”[All Fields] OR (“educational technology”[MeSH Terms] OR “technology”[All Fields]) OR “educational technology”[All Fields]) OR (“communication aids for disabled”[MeSH Terms] OR “communication aids for disabled”[All Fields]) OR (“self-help devices”[MeSH Terms] OR “self-help devices”[All Fields] OR “assistive technology”[All Fields]) OR (“internet”[MeSH Terms] OR “internet”[All Fields]) OR virtual[All Fields] OR digital[All Fields] OR (“computers, handheld”[MeSH Terms] OR “computers”[All Fields] OR “handheld computers”[All Fields] OR (“computers”[All Fields] AND “handheld”[All Fields]) OR “computers, handheld”[All Fields]) OR online[All Fields] OR (“electronics”[MeSH Terms] OR “electronics”[All Fields] OR “electronic”[All Fields]) OR game[All Fields] OR gaming[All Fields] OR chat[All Fields] OR skype[All Fields] OR (“smartphone”[MeSH Terms] OR “smartphone”[All Fields]) OR iPad[All Fields] OR web-based[All Fields] OR ICT[All Fields] OR (“blogging”[MeSH Terms] OR “blogging”[All Fields] OR “blog”[All Fields]) OR (“social media”[MeSH Terms] OR (“social”[All Fields] AND “media”[All Fields]) OR “social media”[All Fields]) OR “online social networks”[All Fields] OR “text messaging”[All Fields] OR “communications media”[All Fields] OR “multimedia”[All Fields])

PsychInfo and CINAHL: (DE “Assistive Technology” OR DE “Electronic Communication” OR DE “Blog” OR DE “Computer Mediated Communication” OR DE “Electronic Learning” OR DE “Social Media” OR DE “Text Messaging” OR DE “Blog” OR DE “Computer Mediated Communication” OR DE “Electronic Learning” OR DE “Social Media” OR DE “Online Social Networks” OR DE “Text Messaging” OR DE “Communication Systems” OR DE “Telephone Systems” OR DE “Communications Media” OR DE “Audiovisual Communications Media” OR DE “Mass Media” OR DE “Multimedia” OR DE “Telecommunications Media” OR DE “Distance Education” OR DE “Internet” OR DE “Mobile Devices” OR DE “Cellular Phones” OR “assistive technology” OR “electronic communication” OR “blog” OR “computer mediated communication” OR “electronic learning” OR “social media” OR “online social networks” OR “text messaging” OR “communications systems” OR “internet” OR “telephone systems” OR “communications media” OR “audiovisual communications media” OR “mass media” OR “multimedia” OR “telecommunications media” OR “distance education” OR “mobile devices” OR “cellular phones” OR “smartphone” OR “computer” OR “technology” OR “digital” OR “e-health”)

Web of Science: (telemedicine OR digital OR video OR telecommunications OR teleconference OR telephone OR technology OR “communication aids for the disabled” OR “educational technology” OR “self-help devices” OR “assistive technology” OR internet OR virtual OR digital OR computers OR electronics OR game OR gaming OR chat OR blog OR Skype OR smartphone OR iPad OR web-based OR ICT OR “social media” OR “online social networks” OR “text messaging” OR “communications media” OR multimedia)

Cochrane Library: (telemedicine OR digital OR video OR telecommunications OR teleconference OR telephone OR technology OR “communication aids for the disabled” OR “educational technology” OR “self-help devices” OR “assistive technology” OR internet OR virtual OR digital OR computers OR electronics OR game OR gaming OR chat OR blog OR Skype OR smartphone OR iPad OR web-based OR ICT OR “social media” OR “online social networks” OR “text messaging” OR “communications media” OR multimedia)

2 **PubMed**: ((“dementia”[MeSH Terms] OR “dementia”[All Fields]) OR “alzheimer’s disease”[All Fields] OR “vascular dementia”[All Fields] OR “frontotemporal dementia”[All Fields] OR “dementia with Lewy Bodies”[All Fields])

PsychInfo and CINAHL: (MM “Dementia” OR MM “AIDS Dementia Complex” OR MM “Dementia with Lewy Bodies” OR MM “Presenile Dementia” OR MM “Semantic Dementia” OR MM “Senile Dementia” OR MM “Vascular Dementia” OR DE “Alzheimer’s Disease” OR “dementia” OR “AIDS dementia complex” OR “dementia with Lewy Bodies” OR “semantic dementia” OR “senile dementia” OR “vascular dementia” OR “Alzheimer’s disease”)

Web of Science: (dementia OR alzheimer’s OR “vascular dementia” OR “frontotemporal dementia” OR “dementia with Lewy bodies”)

Cochrane Library: (dementia OR alzheimer’s OR “vascular dementia” OR “frontotemporal dementia” OR “dementia with Lewy bodies”)

3 **PubMed**: ((caregiv[All Fields] OR caregive[All Fields] OR caregivees[All Fields] OR caregiven[All Fields] OR (“caregivers”[MeSH Terms] OR “caregivers”[All Fields] OR “caregiver”[All Fields]) OR caregiver’[All Fields] OR caregiver’s[All Fields] OR caregivering[All Fields] OR caregiveris[All Fields] OR (“caregivers”[MeSH Terms] OR “caregivers”[All Fields]) OR caregivers’[All Fields] OR caregivers’anxiety[All Fields] OR caregivers’burden[All Fields] OR caregivers’complex[All Fields] OR caregivers’coping[All Fields] OR caregivers’efforts[All Fields] OR caregivers’experiences[All Fields] OR caregivers’guides[All Fields] OR caregivers’interest[All Fields] OR caregivers’perception[All Fields] OR caregivers’perceptions[All Fields] OR caregivers’perseverance[All Fields] OR caregivers’practice[All Fields] OR caregivers’s[All Fields] OR caregivers’spouses[All Fields] OR caregivers’status[All Fields] OR caregivers,[All Fields] OR caregiversas[All Fields] OR caregiversassessing[All Fields] OR caregiverschildren[All Fields] OR caregivership[All Fields] OR caregiversrehabilitation[All Fields] OR caregiverss[All Fields] OR caregiversthe[All Fields] OR caregiverteam[All Fields] OR caregivervoice[All Fields] OR caregives[All Fields] OR caregiving[All Fields] OR caregiving’[All Fields] OR caregivinghood[All Fields] OR caregivingxtemperament[All Fields]) OR (“family”[MeSH Terms] OR “family”[All Fields]) OR partner[All Fields] OR “informal caregiver”[All Fields] OR (“spouses”[MeSH Terms] OR “spouses”[All Fields] OR “spouse”[All Fields]) OR (“spouses”[MeSH Terms] OR “spouses”[All Fields] OR “husband”[All Fields]) OR (“spouses”[MeSH Terms] OR “spouses”[All Fields] OR “wife”[All Fields]) OR “significant other”[All Fields] OR (“family”[MeSH Terms] OR “family”[All Fields]) OR (“caregivers”[MeSH Terms] OR “caregivers”[All Fields] OR “carer”[All Fields]))

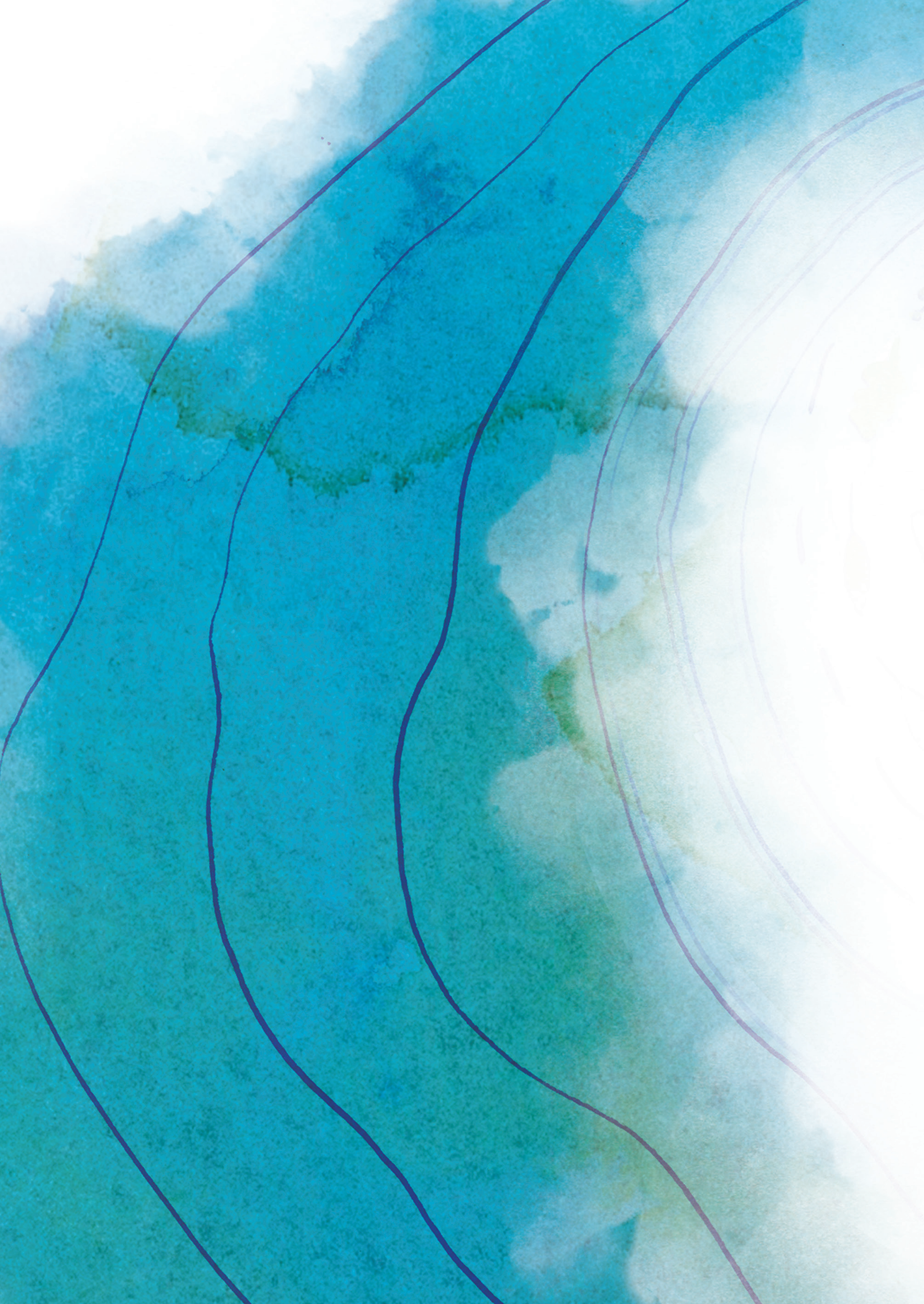
PsychInfo and CINAHL: (DE “Caregivers” OR DE “Spouses” OR DE “Husbands” OR DE “Wives” OR “caregiv*” OR “spous*” OR “husband” OR “wives” OR “wife” OR “family” OR “partner” OR “carer”)

Web of Science: (caregiv* OR carer OR family OR partner OR spouse OR husband OR wife OR “significant other”)

Cochrane Library:(caregiv* OR carer OR family OR partner OR spouse OR husband OR wife OR “significant other”)

4 #1 AND #2 AND #3

Further Supplementary Material (Appendix B) to this article can be found online at https:// doi.org/10.1016/j. invent.2018.07.002.



Chapter 10

General Discussion

Complexity of health and everyday life

As researchers and health care professionals, it is our intention to understand and support individuals as well as possible. While the wish to depict a complete picture of a person's being might be an utopian ideal, it remains important to critically reflect on available methods, be aware of their strengths and limitations, and also consider new approaches. Furthermore, integrating various aspect of a person's life instead of focusing on only one or two elements allows us to uncover connections, patterns, and networks. A holistic view on health in combination with a method suitable to capture the complexity of everyday life may then bring us one step closer to reaching our intention.

The Experience Sampling Method (ESM) is uniquely suited to contribute to depicting variables in a fine-graded and dynamic way as it (i) measures various concepts within one questionnaire, (ii) collects data in everyday life, (iii) has a high ecological validity, and (iv) illustrates fluctuations and networks of variables [1]. Expanding its use from psychiatric and mental health departments [2] into the sectors of elderly care and neurological diseases may greatly contribute to better understanding of, and thus, better support for older adults.

Summary of main findings

This thesis expands the insight into daily patterns of older adults in different target groups and has a special focus on affective and cognitive functioning and technology use.

Part one contains different methodologies that inform on various aspects of everyday life. As such, the relationship between a self-report and observational tool assessing the ability to use everyday technology (ET) in people with mild cognitive impairment (MCI) or early dementia was studied (**Chapter 2**). Results showed that people with early dementia are able to accurately reflect on their abilities to use ET and both methods should be combined to gather a comprehensive view on technology use.

In **Chapter 3**, these recommendations were taken into account to evaluate the feasibility smartphone-based experience sampling in people with MCI. The majority of participants were able to use the ESM well and reflected positively on the approach. However, a small number of participants dropped out due to cognitive problems and many contacted people with MCI were not in possession of smartphones, indicating a limited general applicability. The usability of momentary data was demonstrated on a group- and individual level and revealed great variability within- and between- subjects.

To assess cognition in an objective manner in everyday life, momentary cognition tasks were developed to measure processing speed (**Chapter 4 & 5**) and visual spatial memory functions (**Chapter 5**), and tested in healthy adults to determine feasibility and validity. Initial evidence could be provided for the general feasibility and contextual validity, but more research is suggested to advance the tasks further.

Part two moved on to the topic of interventions to support well-being through technology-based self-monitoring such as ESM. A narrative synthesis systematic review was conducted to provide an overview on how digital self-monitoring can be used in intervention set-ups to promote health in middle-aged and older adults (**Chapter 6**). Key findings were that of interventions focused greatly on middle-aged adults, prospective set-ups should include both online and face-to-face feedback as well as social health elements, and more research is needed on intervention mechanisms, the sustainability of intervention effects, and lasting lifestyle changes.

Therefore, the mechanisms of the ESM-based ‘Partner in Sight’ intervention for spousal carers of people with dementia were studied in **Chapter 7**. This project used momentary data collected throughout the intervention and focused on changes in carer’s daily activities as well as their link with affect and activity-related stress. Results showed that only carers that used the ESM and also received personalized feedback changed their behavior, namely by engaging more in passive relaxation activities. This change, however, was aligned with mixed emotions.

The sustainability of positive effects on carer’s well-being of the selfsame intervention after six months was also evaluated (**Chapter 8**). Here, positive intervention effects faded and prospective interventions may need to include additional features. For example, micro interventions or booster sessions could be considered.

In part three, the aspect of implementing interventions into communities was explored through a systematic review focusing on eHealth interventions for informal carers of people with dementia (**Chapter 9**). Findings showed that most studies focused on the eHealth applications and characteristics of the carers, while the organizational level and wider context received little attention. Future research needs to bridge the gap between research and practice.

This final chapter discusses the main findings, highlights methodological and conceptual considerations, clinical implications, and directions for future research.

Applicability of the ESM in older adults and people with MCI

While middle-aged adults already benefit from the ESM and other digital self-monitoring tools [2, 3], the application of the ESM in seniors remains rarer. The literature review described in **Chapter 6** reveals that only two ESM-based intervention studies included individuals with an average age older than 65 years. Furthermore, the ESM is feasible in people with certain neurological condition, such as stroke or brain damage [4, 5], but, to our knowledge, individuals with MCI did not get in contact with this approach until now.

Applying a new, technology-based approach in aging populations needs to be carefully studied as both desirable but also negative, disturbing, or excluding effects may appear [6, 7]. The results from **Chapter 2** suggest that a thorough evaluation including both self-perceived reports and observations is appropriate to understand the ability of older adults with cognitive problems to use ETs (e.g. smartphone). Accordingly, both methods were combined to gain a comprehensive view on the feasibility of smartphone-based experience sampling in people with MCI (**Chapter 3**). Results show that the majority of this MCI sample was able to handle the ESM app, compliance rate was high, and subjective ratings were positive, indicating that the ESM is generally feasible in people with MCI.

However, a minority of participants had difficulties remembering the study instructions or to carry their smartphones, and thusly dropped out. Furthermore, many contacted individuals with MCI were not in possession of smartphones or did not feel comfortable to participate in a technology-based study. An eHealth approach such as the ESM should rely on a technology that can be used and that most individuals perceive as relevant.

The presented recruitment bias indicates a current gap in the applicability of the ESM in the general MCI population, which might be rather temporary as smartphone ownership in seniors grows. A U.S. report showed that in 2013, 29% of adults aged 65+ owned a smartphone and ownership increased to 59% by 2016 [8]. Technical device adoption may be higher in individuals in their 50's and 60's, but also people in their 70's are in possession of various ETs (see Figure 1 [9]).

When looking at smartphone use in particular, it is furthermore important to highlight that tracking health and fitness using apps/websites (60-69yrs.: 24%; 70+ yrs.: 15%) is an activity some older adults already engage in [9]. This aspect suggests that the ESM and other self-monitoring approaches may prospectively be of interest for elderly populations. Admittedly, these numbers do not reflect people with MCI specifically, but if technologies become overall more interesting and relevant for seniors, it can be assumed that this trend includes people with various health issues. Potentially, individuals with health problems might even be more aware of the need to invest in their health and particularly motivated to track their well-being closely even in the context of or despite cognitive problems.

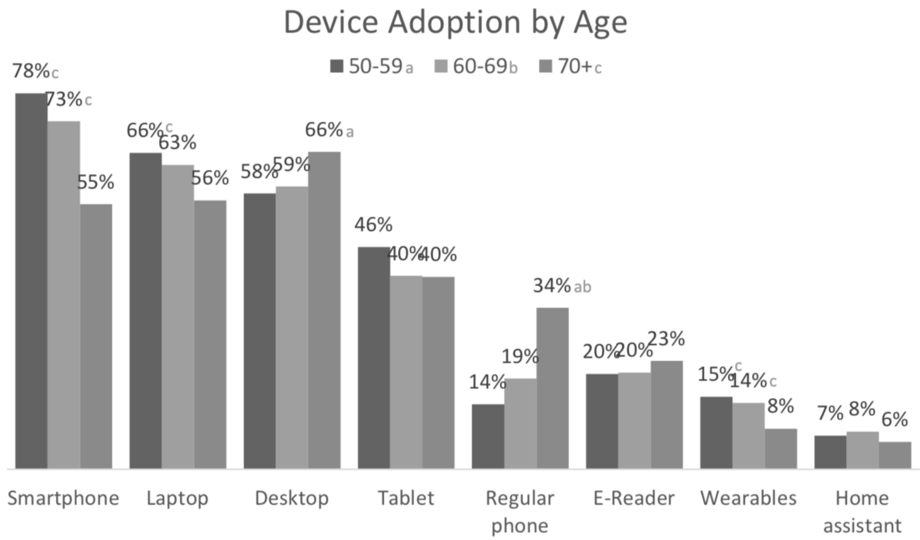


Figure 1. Device adoption by age in n=1520 adults 50+ (Anderson (2017)); letters represent a significant difference between groups (95% confidence level) [9].

Involving people with cognitive impairments and dementia in eHealth research is highly recommended and **Chapter 2** showed that people with mild dementia were able to accurately rate their ability to use ET. Asking people with cognitive impairment such as dementia for their input in the development of new technologies is thought to be not only important to ensure feasibility and usability, but can also result in feelings of empowerment [10]. Nevertheless, challenges such as ethical (i.e. informed consent) and practical issues (i.e. communicating thoughts/ideas) need to be managed and researchers should remain sensitive to peoples' special needs throughout the process [11].

Measuring cognition in everyday life

Cognition is a relevant element of daily functioning, especially in older adults as the risk for cognitive decline increases with age. Therefore, it will be beneficial to not only measure problems with, for example, memory, attention, or concentration, in everyday life through ESM questions where individuals subjectively indicate complaints (e.g. '*Since the last beep, I had memory problems*' rated on a 5-point Likert-scale; **Chapter 3**), but also by using more objective forms of assessment. **Chapter 4** and **Chapter 5** provided initial evidence that integrating momentary cognition tasks into an ESM questionnaire is feasible in healthy individuals of various ages. Particularly the momentary Digit Symbol Substitution Task (mDSST) seems promising for future studies as it is age-sensitive and captures between- and within-person variance.

Generally, cognitive functioning captured with such an approach varies from the outcome of traditional neuropsychological tests. The term 'contextual cognition' is here introduced, which refers to the idea that cognition is a dynamic concept affected by various momentary contextual factors such as mood, the environment (i.e. location, social company, distractors), substances (i.e. coffee, alcohol), or bodily functions (i.e. fatigue, sleeping patterns, brain alterations). When using traditional neuropsychological assessments, the context is kept as calm and sterile as possible to not distract individuals from performing with their maximum capacity [12]. In everyday life, however, a great number of stimuli are present, including sounds, smells, lights, movement, or tactile impulses. Additionally, internal states such as worries, excitement, or stress can impact one's ability to pay attention, concentrate, or remember. Therefore, viewing cognitive functioning in context reflects a different aspect of cognition than what is currently captured with neuropsychological tests. In fact, contextual cognition may explain why some help-seeking individuals at memory clinics report subjective cognitive problems while performing cognitively 'normal' on traditional neuropsychological tests. As the suggested low ecological validity of neuropsychological tests indicates [12], these clinical assessments may simply not depict the person's reality. Therefore, momentary cognition tasks could be valuable addition to traditional neuropsychological tests to get a comprehensive view on an individual's functioning.

For prospective momentary cognition task development and use, recommendations comprehend the involvement of a multi-disciplinary team and adjusting the level of difficulty to individual cognitive abilities (**Chapter 5**). Adjustments have also been suggested for technologies targeting physical functioning (e.g. exergaming) [13] and can prevent frustration or stimulate motivation. Gamification elements and reward systems may also be included to improve data collection and quality in mobile settings [14], thus making momentary tasks more enjoyable and positively contributing to adherence.

No norm tables or information on 'standards' for momentary cognition tasks or ESM data of older adults are available yet, but might also not be the optimal form of comparison in this case. Individuals can be seen as their own controls as repeated momentary data collection over several days results in the possibility to compare within-subjects. Such a rich, individual dataset can be used by clinicians to understand their clients better, tailor treatment, or monitor rehabilitation [15]. Future studies may explore the proposed concept of 'contextual cognition', for example by comparing ESM data with more traditional tools, investigating different patient populations, and gathering opinions from researchers in cognitive sciences on this approach.

Finally, the processing and translation of cognitive and other momentary variables into meaningful and understandable graphs needs to be studied. In technical industries, for example the Fitbit brand, passive self-monitoring via smartwatches focusses on physical activity [16] and data presentations appear technically mature (Figure 2). The advancements of momentary cognition tasks and active ESM self-monitoring in general might benefit from this acquired expertise. Combining the knowledge of different sectors may facilitate the use of ESM data in memory clinics and neurology in the future.

Figure 2. Data presentation of physical health aspects using the Fitbit smartwatch (Author's personal data; 2020).

Relevance of social health and social context

Not only within Fitbit or other popular self-monitoring approaches, but also in clinical practice, the ‘traditional view’ on health as a form of optimal physical functioning remains dominant. This matter was also portrayed in **Chapter 6**, as every self-monitoring intervention covered questions on physical health. However, the attention towards a holistic health view including psychological and social aspects increases [17]. In the field of dementia, for instance, social health has been emphasized to be an aspect that needs further attention in research and clinical practice [18, 19].

A recent review showed that mobile health apps contribute to social health by facilitating communication and interaction between people with dementia and their families or friends [20]. Using the ESM, certain social aspects of everyday life may be detected, such as the amount of appreciation for company (**Chapter 6**), but more studies are needed to optimise the measurement and promotion of social health [21]. Social health may include the pure presence, expressed appreciation, support received, or activities performed together with others. While a partner or friend can promote well-being, he/she may also hinder the realization of a healthy lifestyle or optimal functioning. In the context of caregiving and social interactions, research showed that family carers of people with dementia who approach problem behaviour of the care recipient with impatience, irritation, or confusion, thus using a so called non-adaptive management style, actually seem to trigger and encourage even more hyperactive symptoms [22].

In **Chapter 7**, spousal carers who aimed to engage more in activities that elicit positive emotions had to harmonize their intentions with the social context, specifically the presents of the care recipient, which might explain the mixed emotions experienced. In line with this point on social context is also a finding from **Chapter 5,** where company had a negative effect on cognition, as participants made more mistakes and performed slower when other individuals were present. Prospective studies may include social health aspects into interventions set-ups, explore measurement approaches, study mechanisms, and aim to translate the theoretical structure of health as a multi-layered and dynamic concept [23] into a practical applicability.

ESM-based intervention set-ups and personalized feedback

To support individuals in everyday life, experience sampling within an intervention can be applied. According to the social cognition theory, self-monitoring can raise awareness for own emotions and behaviors and promote a behavioral change [24]. Momentary data may also be used to facilitate a conversation between an individual and health care professional to improve self-management and thus support well-being. Affirmatively, **Chapter 6** showed that 96% of all technology-based self-monitoring interventions included in this review reported some form of health improvement.

Delivering interventions to older adults via technology can provide assistance in moments when it is most needed and can be cost-effective [25, 26]. Importantly, the technology of choice must be usable and relevant (**Chapter 2**), but also mobile (**Chapter 6**). Stationary options such as computers or webpages not accessible via smartphones will limit the insight into daily aspects and use in various contexts.

In addition to the active, technology-based self-monitoring, the importance of personal contact between healthcare professionals or researchers and the individual remains. Communication with participants is not only appreciated and pleasant [27], it can also help to identify negative consequences of digital self-monitoring (e.g. unpleasant awareness for own cognitive difficulties (**Chapter 3**)). Ongoing communication between the individual and healthcare professional may prevent frustration with the technology, maintain motivation to adhere to the intervention, and promote long-lasting health improvements.

Another key element for the design of prospective ESM-based intervention include automatic as well as personal feedback following a blended care principle (**Chapter 6**). Blended care combines online and face-to-face support and has several benefits: (i) individuals can continue the intervention in a structured way without the health care professional present, and (ii) personal contact enables additional guidance if needed [28, 29]. ESM self-monitoring in combination with personalized feedback could increase awareness for activities that elicit positive emotions and thus stimulate increased engagement in these enjoyable activities [30, 31]. **Chapter 7** confirms these mechanisms as spousal carers who used the ESM and received personalized feedback indeed engaged more in passive relaxation activities. This observed behavioural change was somewhat stressful for the participating carers, but also showed to be associated with decreased negative affect.

Conclusively, personalized feedback is crucial to enable a behavioural change towards activities that support coping with caregiving, but changing ones' behaviour while providing care for a person with dementia is challenging. While certain studies emphasize the need to focus on positive aspects of caregiving [32, 33], this finding highlights the situational complexity and multi-layered nature of carer's feelings in everyday life (**Chapter 7**). It seems necessary to acknowledge and discuss both positive and negative aspects of everyday life and within interventions without judgement. ESM can help individuals to reflect on their daily lives [3] and techniques such as mindfulness or acceptance and commitment therapy (ACT) could be beneficial to embrace both unpleasant feelings or situations and enjoyable moments [34, 35].

Lastly, the interventions need to be person-tailored, adaptive to individual preferences and needs, and offer long-term support. Just-in-time booster sessions, micro interventions, or ad-hoc counselling should be considered (**Chapter 8**). The results of **Chapter 6** reveal furthermore that more research on self-monitoring interventions for disease prevention, lasting lifestyle changes, mechanisms of intervention effects, and their sustainability is needed. Qualitative interviews or studies using momentary data may enable the understanding of participants' experiences throughout interventions. Alternatively, practical studies comparing different set-ups and their effects can inform on intervention modalities.

Implementation and future directions

While it may be desirable to implement an effective intervention, not all research interventions are designed and meant for the wider societal context. Research into eHealth intervention for family carers of people with dementia often focuses on the eHealth application and carers, while the organisational and wider contextual factors receive little attention (**Chapter 9**). Certainly, collecting evidence on intervention effects and mechanisms contributes to new knowledge and therefore effectiveness studies without a long-term implementation plan are valuable in itself. The 'Partner in Sight' intervention, for instance, improved our understanding of carer's daily patterns (**Chapter 7**) and supported carers well-being for several months in a research context (**Chapter 8**) [36]. However, an implementation plan including determinants associated with the wider context (e.g. care policy, country-specific problems, and ethics) was lacking and could have been useful to eventually translate the intervention into practice.

To support older adults in managing their well-being sustainably, health care professionals may need to provide continuous assistance and be available in moments when it is most needed. eHealth could enable these requirements, but implementing eHealth into practice also means that health care professionals need to adjust their current routines. Adapting a new service or tool, may it be technology-based or otherwise, requires resources such as time, money, and knowledge. Clinicians, psychologists, or nurses in neurological departments are currently not familiar with self-monitoring tools such as ESM apps and as mentioned resources are limited, motivating health care professionals to use eHealth can be a challenge.

Still, implementation studies need to focus on closing the gap between research and practice for those interventions and tools that seem suitable for the wider context. Furthermore, policy makers and health insurance companies need to approve and facilitate the use of eHealth including ESM on an organisational and community level. The responsibility to implement eHealth should be tackled on all levels. Including not only researchers, clinicians, and users, but also stakeholders and financial gatekeepers early on in the research process is advised for eHealth implementation studies [37]. Studies also identified determinants for the implementation of eHealth in a municipality context [38] and developed an evidence-based strategy, business model and implementation plan [39]. Thus, selected interventions, programs, or tools may have a greater chance to be successfully implemented in the future.

Methodological considerations

As human life expectancy increases worldwide [40], understanding and supporting healthy aging in everyday life is a relevant and timely topic. In combination with the ESM and technology use, the studies of this dissertation advance an innovative research field. Throughout all studies, a multi-disciplinary team of professionals was involved in the construction and execution including researchers with a background in psychology, neuropsychology, neuropsychiatry, occupational therapy, ESM experts, and statistics. Thus, the findings could be discussed from different perspectives and ensured a high level of relevance for various professions. Multi-method approaches using self-reports, observations, literature searchers, and momentary data collection allowed to illustrate research questions from complementary angles. Additionally, not only the feasibility, usability, and validity of tools but also the composition of interventions, their mechanisms and sustainability, as well as aspects of implementation were studied. Finally, the populations varied from people with MCI, early dementia, family/spousal carers, and healthy individuals and thus tapped into different aspects of the aging process.

Several limitations need to be acknowledged. First, a recruitment bias is likely to be present in several studies. **Chapter 2-5, 7, and 8** involved the use of technologies and therefore individuals who are reluctant to use complex items such as information and communication technologies/smartphones might have declined participation. Furthermore, ESM is time consuming and spousal carers of people with dementia (**Chapter 7 and 8**) exposed to a great amount of caregiving burden might have been too busy to participate. Therefore, the results may not represent the group of carers as a whole. In **Chapter 4 and 5**, individuals were younger, healthier, and higher educated. Thus, the feasibility and usability of momentary cognition tasks cannot be generalized to older and cognitively impaired individuals without due consideration, and more studies are needed.

Second, technology develops rapidly and new devices, items, or updates are available time and again. In **Chapter 2**, tablets were not reflected by this group of participants even though tablets may be or become relevant for older adults [41]. In addition to active ESM self-monitoring, passive self-monitoring via smartwatches or pedometers may prospectively be studied in aging populations as mentioned above.

Third, many contacted individuals with MCI were not in possession of a smartphone (**Chapter 3**) and three participants were unable to use the ESM app. Therefore, technology-based innovations such as ESM or other digital self-monitoring approaches may be perceived as non-relevant or exclusive by some older individuals. Strengthening the field of eHealth through studies, such as the ones presented in this thesis, can lead to injustice in treatment applicability [42] and represent an ethical issue. Age-specific and culturally appropriate training to use technologies and the internet is suggested [43]. Nevertheless, it is important to offer a diverse pallet of interventions of eHealth and non-eHealth approaches to best fit the capabilities and wishes of a diverse population. The cognitive accessibility and individual relevance needs to be kept in mind [44].

Finally, the recruitment was challenging resulting in relatively small sample sizes in **Chapter 3 and 7**. Similarly, the number of drop-outs due to care recipients deaths, transition into care homes, or carer's feelings of being too busy resulted in a small sample size in **Chapter 8**. Also, no control group was included in **Chapter 2 and 3**, which limits the expressiveness of the findings to some extent.

Concluding remarks

The ESM allows for depiction of various aspects of everyday life of older adults with and without cognitive impairments in a fine-graded and dynamic way. As the ESM and many other innovations are technology-based, the challenge remains to ensure that all older individuals can use new eHealth services and tools not only in terms of physical and cognitive capability, but also personal relevance and sustainable implementation. If facilitated in an inclusive way, digital self-monitoring approaches may prospectively improve our understanding of real-world experiences and daily challenges of aging populations and thus offer a highly personal and unique approach to treat, prevent, and rehabilitate.

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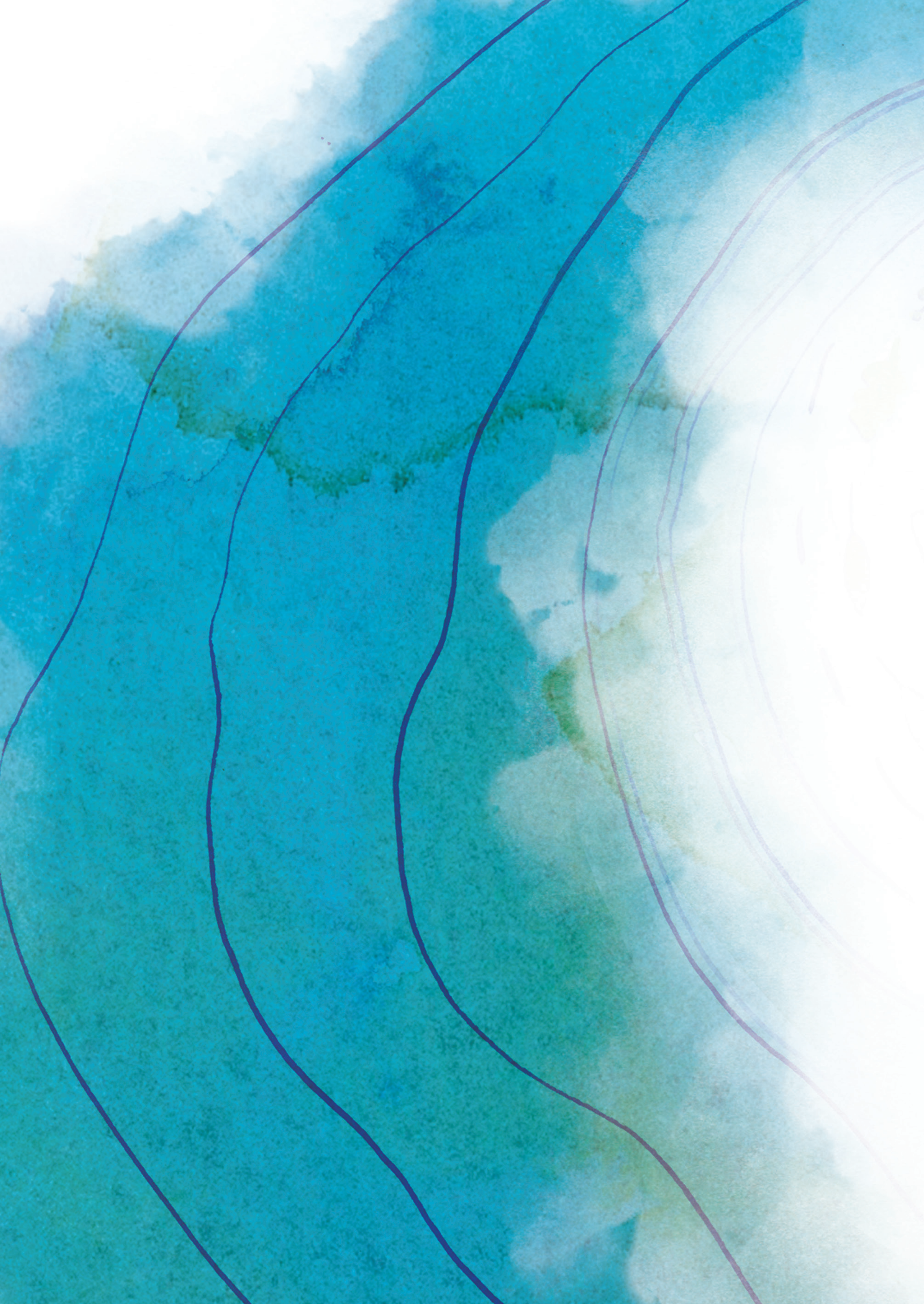
Addendum



Addendum

Summary

Summary

With age, the risk that an individual needs to adjust to a life with cognitive impairments or dementia increases – either by being affected him/herself or by becoming an informal carer providing daily assistance. These adjustments in everyday life can be challenging and complex. For researchers and health care professionals, it is important to understand an individual's reality as well as possible to provide optimal support.

Various methods are available to gain insight into the different health aspects and daily patterns of individuals, including self-reports, proxy-reports, neuropsychological assessments, or observations. While these methods are widely used, reliable, and valid, they also have their limitations. For example, self-reports rely on accurate memory recall and neuropsychological assessments take place in calm, artificial clinical environments. A diary approach collecting information in moments at which they occur can provide a more fine-graded picture.

The experience sampling method (ESM) is an innovative, technology-based, diary approach that is still rarely used in senior populations. The ESM enables individuals to report on their emotions, behaviours, and context in real-life situations. Using technology such as a digital diary to improve health is called 'eHealth'. eHealth may be cost-effective, can facilitate communication with health care professionals, and improve well-being. However, eHealth approaches can also result in practical and ethical issues, for example, if the technology is not relevant for or usable by the older person. Therefore, a careful evaluation of a technology-based approach such as the ESM is important.

This thesis aims to improve the understanding of everyday life in older adults of different target groups with a special focus on cognitive and affective functioning and technology use. A general introduction including background information, study rationales, research questions, and the thesis outline is provided in **Chapter 1**.

Part I focusses on *feasibility and usability* and contains different methodologies that inform on various aspects of everyday life. Thus, the relationship between a self-report and observational tool assessing the ability to use everyday technology (ET) in people with mild cognitive impairment (MCI) (n=41) or early dementia (n=38) is studied in **Chapter 2**. Results show that people with early dementia are able to accurately reflect on their abilities to use ET, but both methods should be combined to gather a comprehensive view on technology use.

In **Chapter 3**, these recommendations are taken into account to evaluate the feasibility of smartphone-based experience sampling in people with MCI. A majority of participants (n=18) is able to use the ESM well and reflects positively on the approach. However, a small number of participants (n=3) drop out due to cognitive problems. Also, many for this study contacted people with MCI are not in possession of smartphones, indicating a limited general applicability. The usability of momentary data is demonstrated on a group- and individual level

A

and reveals great variability within- and between-subjects.

To assess cognition in an objective manner in everyday life, momentary cognition tasks are developed to measure processing speed (**Chapter 4 & 5**) and visual spatial memory functions (**Chapter 5**), and tested in healthy adults to determine feasibility and validity. Initial evidence could be provided for the general feasibility and contextual validity, but more research is suggested to advance the tasks further.

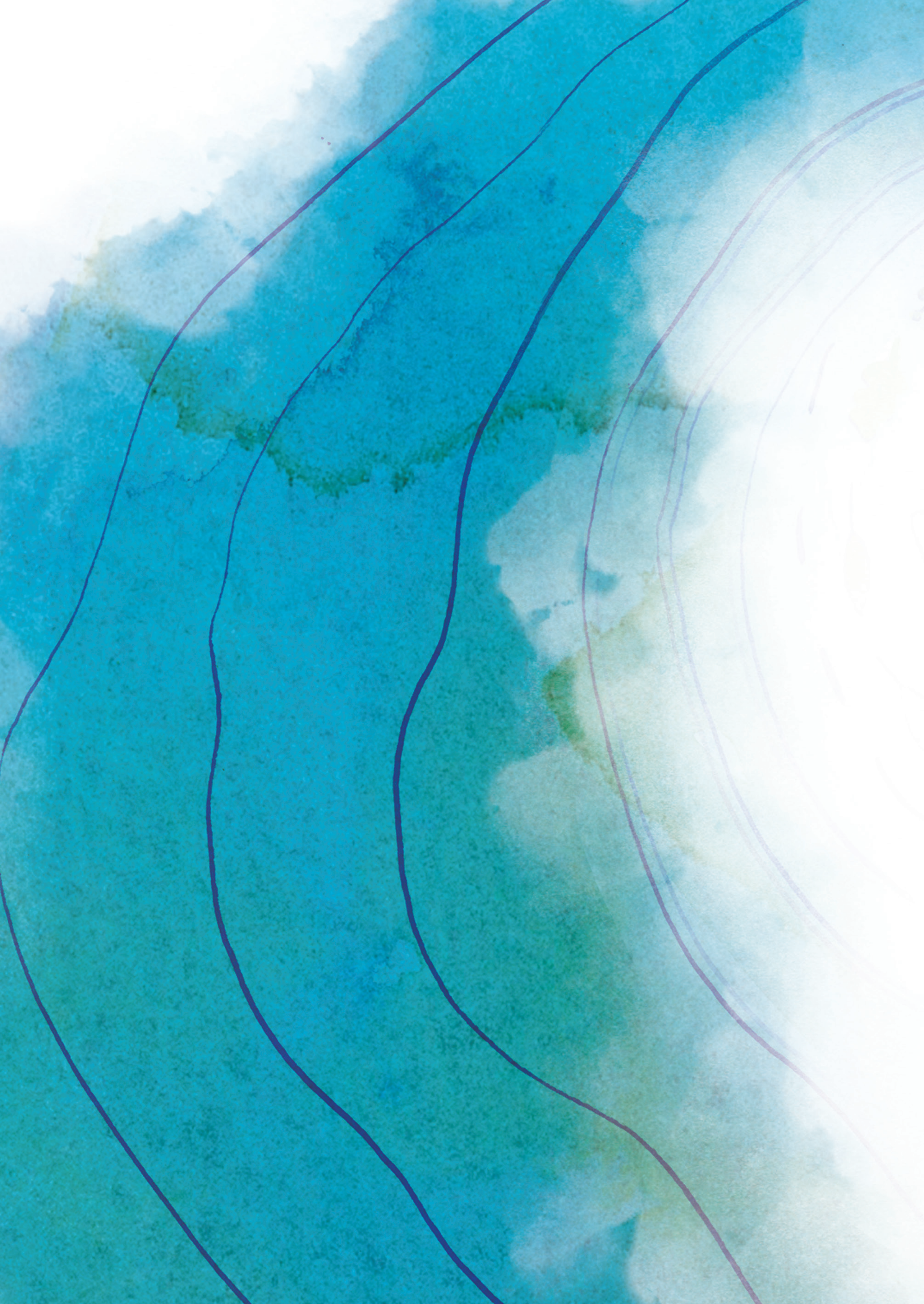
Part II focuses on to the topic of *interventions and effectiveness.* A narrative synthesis systematic review is conducted to provide an overview on how digital self-monitoring can be used in intervention set-ups to promote health in middle-aged and older adults (**Chapter 6**). Key findings highlight that interventions focus greatly on middle-aged adults, prospective set-ups should include both online and face-to-face feedback as well as social health aspects. Furthermore, more research is needed on intervention mechanisms, the sustainability of intervention effects, and lasting lifestyle changes.

Therefore, the mechanisms of the ESM-based 'Partner in Sight' intervention for spousal carers of people with dementia are studied in **Chapter 7**. This project uses momentary data collected throughout the intervention and focuses on changes in carer's daily activities as well as their link with affect and activity-related stress. Results show that only carers that use the ESM and also receive personalized feedback change their behaviour, namely by engaging more in passive relaxation activities. This change, however, is aligned with mixed emotions.

The sustainability of positive effects on carer's well-being of the self-same intervention after six months is also evaluated (**Chapter 8**). Unfortunately, positive intervention effects fade and prospective interventions may need to include additional features. For example, micro interventions or booster sessions could be considered.

In **Part III**, aspects of implementing interventions are explored through a systematic review focusing on eHealth interventions for informal carers of people with dementia (**Chapter 9**). Findings show that most studies concentrate on the eHealth applications and characteristics of the carers, while the organizational level and wider context receives little attention. Future studies need to bridge the gap between research and practice.

In **Chapter 10,** the main findings, highlights methodological and conceptual considerations, clinical implications, and directions for future research are discussed.



Addendum

Zusammenfassung

Zusammenfassung

Im Alte steigt das Risiko, dass sich eine Person an ein Leben mit kognitiven Einschränkungen oder Demenz anpassen muss – entweder weil man selbst erkrankt ist oder weil man sich um jemanden kümmert, der betroffen ist. Diese Veränderungen im Alltag können herausfordernd und komplex sein. Für Forscher und Fachkräfte im Gesundheitswesen ist es wichtig, die Realität von Individuen so gut wie möglich zu verstehen und optimale Unterstützung zu bieten.

Es gibt viele Methoden, um einen Einblick in die verschiedenen Gesundheitsaspekte zu erhalten und täglichen Strukturen einer Person zu verstehen. Dazu zählen Selbstauskünfte, Auskünfte von Verwandten oder Freunden, neuropsychologische Gutachten, und Beobachtungen. Obwohl diese Methoden weitverbreitet und valide sind, haben sie dennoch ihre Grenzen. Zum Beispiel sind Selbstauskünfte auf ein akkurates Gedächtnis angewiesen und neuropsychologische Tests werden in einer ruhigen, klinischen Umgebung durchgeführt. Ein Tagebuch-Ansatz, bei dem Informationen in den Momenten gesammelt werden, in denen sie stattfinden, könnte ein detailliertes Bild beschreiben.

Die „Experience Sampling Method“ (ESM) (wörtlich ‚Erfahrungs-Sammlung Methode‘, ein digitales Tagebuch) ist eine innovative, auf technologie-basierende Vorgehensweise, die noch recht selten bei Senioren verwendet wird. Die ESM ermöglicht es Individuen, über ihre Emotionen, ihr Verhalten, und den Kontext im echten Leben zu berichten. Technologien wie diese digitale Tagebuch-Methode zu verwenden, um Gesundheit zu verbessern, nennt man ‚eHealth‘. eHealth kann kostengünstig sein, die Kommunikation mit Fachkräften im Gesundheitswesen erleichtern und Wohlsein verbessern. Allerdings können eHealth Ansätze auch praktische und ethische Probleme mit sich bringen, zum Beispiel wenn die Technologie für den älteren Menschen nicht relevant oder verwendbar ist. Daher ist es wichtig, auf technologie-basierende Ansätze wie die ESM gründlich zu evaluieren.

Diese Dissertation zielt darauf ab, eine verbesserte Einsichten in das tägliche Leben älterer Menschen von verschiedener Zielgruppen zu ermöglichen. Speziell die kognitive und affektive Funktionsweise sowie der Nutzen von Technologie steht dabei im Vordergrund. Eine generelle Einleitung mit Hintergrundinformationen, rationellen Überlegungen, den Forschungsfragen und der Gliederung der Thesis sind in **Kapitel 1** beschrieben.

Teil 1 fokussiert sich auf die *Durchführbarkeit und Nutzbarkeit* von unterschiedliche Methoden, die über die verschiedenen Aspekte des Alltags Auskunft geben. Demnach wird in **Kapitel 2** das Verhältnis von einer Selbstauskunft zu einem auf Beobachtungen basierenden Instrument untersucht, die beide die Fähigkeit von Menschen mit leichten kognitiven Störungen (Englisch: mild cognitive impairment (MCI)) (n=41) und Demenz (n=38) beurteilen, alltägliche Technologien zu verwenden. Die Ergebnisse zeigen, dass Menschen mit leichter

Demenz ihre eigene Fähigkeit alltägliche Technologien zu verwenden akkurat einschätzen, aber beide Methoden sollten kombiniert werden, um eine umfangreiche Einschätzung vom technologischem Nutzen im Alltag zu erhalten.

In **Kapitel 3** werden diese Empfehlung in der Beurteilung der Durchführbarkeit von digitalen Handy-Tagebüchern in Menschen mit MCI berücksichtigt. Dem Großteil der Teilnehmer (n=18) ist es möglich, die ESM zu verwenden und sie haben positive Reflektionen bezüglich dieses Ansatzes. Allerdings beendet ein kleiner Teil der Teilnehmer (n=3) aufgrund von kognitiven Problemen die Studie nicht. Des weiteren sind viele, für diese Studie kontaktierte Personen mit MCI nicht im Besitz eines Handys, was auf eine limitierende Anwendbarkeit hindeutet. Die Nutzbarkeit von Tagebuch-Daten ist auf einer Gruppen- und individuellen Ebene demonstriert und deckt eine funktionelle Varianz in der Stichprobe auf.

Um Kognition objektive im Alltag messen zu können, werden kognitive Tagebuch-Tests, die Verarbeitungsgeschwindigkeit (**Kapitel 4 &5**) und visuell-räumliche Gedächtnisfunktionen (**Kapitel 5**) erfassen , entwickelt und beurteilt. Deren Durchfuhrbarkeit und Aussagekraft wird in gesunden Erwachsenen getestet. Erste Beweise können die generelle Durchführbarkeit und kontextuelle Aussagekraft bestätigen, aber weitere Forschung ist nötig, um die Tests weiterzuentwickeln.

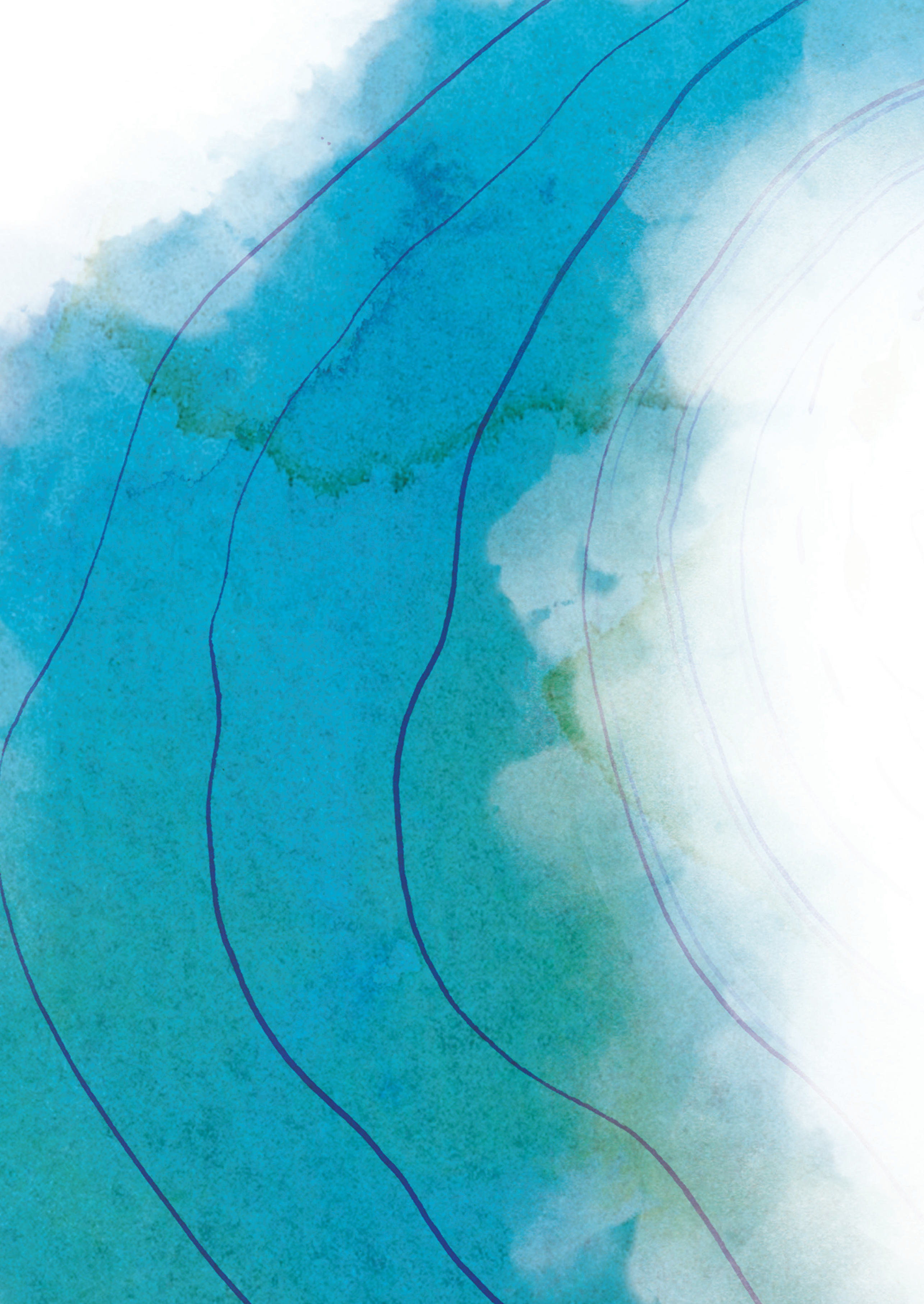
Teil 2 konzentriert sich auf das Thema *Interventionen und Effektivität*. Eine narrative Synthese eines systematischen Reviews ist durchgeführt, um eine Übersicht bereitzustellen, die darlegt, wie digitale Selbstbeobachtung (English: self-monitoring) in Interventionen genutzt werden kann, um die Gesundheit von Menschen mittleren Alters und Senioren zu fördern (**Kapitel 6**). Wesentliche Erkenntnisse betonen, dass Interventionen sich bisher primär auf Menschen mittleren Alters beziehen und dass zukünftige Interventionen sowohl online, als auch persönliches Feedback und soziale Gesundheitsaspekte beinhalten sollten. Außerdem ist mehr Forschung nötig, die sich auf Interventionsmechanismen, die Nachhaltigkeit von Interventionseffekten, und anhaltenden Veränderungen des Lebensstils fokussiert.

Dem Folgend werden die Mechanismen einer Tagebuch-Intervention (Englischer Name: ‚Partner in Sight‘) für Ehepartner von Menschen mit Demenz in **Kapitel 7** untersucht. Dieses Projekt verwendet Tagebuch-Daten der Ehepartner, die während der Intervention gesammelt wurde, und konzentriert sich auf Verhaltensveränderungen und die Verbindung zwischen diesen Veränderungen und Emotionen sowie Stress. Ergebnisse zeigen, dass nur Partner, die sowohl das ESM-Tagebuch verwendet, als auch persönliche Feedbacks erhalten haben, ihr Verhalten verändern. Demnach beschäftigen sie sich häufiger mit passive Entspannungsaktivitäten. Diese Verhaltensveränderung geht allerdings mit gemischten Gefühlen einher.

Die Nachhaltigkeit der positiven Effekten derselben Tagebuch-Intervention in Hinblick auf das Wohlbefinden der Partner nach mehreren Monaten wird ebenfalls untersucht (**Kapitel 8**). Leider schwinden die positiven Effekte nach 6 Monaten und zukünftige Interventionen für Partner von Menschen mit Demenz sollten weitere Elemente mit einbauen, wie zum Beispiel Micro-Interventionen oder ‚Booster' Module.

In **Teil 3** werden Aspekte der *Implementation* von Interventionen durch einen systematischen Review exploriert, der sich auf eHealth Interventionen für pflegende Angehörige von Menschen mit Demenz fokussiert (**Kapitel 9**). Die Resultate zeigen, dass die meisten Studien sich auf den eHealth Ansatz oder Charakteristika der pflegenden Angehörigen konzentrieren, während die organisatorische Ebene und der weitreichende Kontext wenig Aufmerksamkeit erhalten. Zukünftige Studien sollte die Lücke zwischen Forschung und Praxis füllen.

Kapitel 10 diskutiert die Ergebnisse und zeigt methodische und konzeptionelle Überlegungen, klinische Implikationen, sowie Richtungen für zukünftige Forschung auf.



Addendum

Samenvatting

Samenvatting

Het risico toe dat een individu zich moet aanpassen aan een leven met cognitieve stoornissen of dementie neemt toe met de leeftijd - hetzij door zelf getroffen te worden, hetzij door mantelzorger te worden die dagelijks hulp verleent. Deze aanpassingen aan het dagelijks leven kunnen uitdagend en complex zijn. Voor onderzoekers en zorgprofessionals is het belangrijk om de realiteit van een individu zo goed mogelijk te begrijpen om optimale ondersteuning te bieden.

Er zijn verschillende methoden beschikbaar om inzicht te krijgen in de verschillende gezondheidsaspecten en dagelijkse patronen van individuen, waaronder zelfrapportages, proxyrapporten, neuropsychologische beoordelingen of observaties. Hoewel deze methoden veel gebruikt, betrouwbaar en valide zijn, hebben ze ook hun beperkingen. Zelfrapportages vertrouwen bijvoorbeeld op nauwkeurige geheugenherinnering en neuropsychologische beoordelingen vinden plaats in rustige, kunstmatige klinische omgevingen. Een dagboekbenadering die informatie verzamelt op het moment dat de gebeurtenissen zich voordoen, kan een gedetailleerder en verfijnder beeld opleveren.

De ‘Experience Sample Method’ (ESM) is een innovatieve, op technologie gebaseerde dagboekbenadering die tot op heden weinig gebruikt wordt bij ouderen. ESM stelt individuen in staat om te rapporteren over hun emoties, gedrag en context in situaties uit het echte leven. Het gebruik van technologie, zoals het digitale dagboek om de gezondheid te verbeteren, wordt ‘eHealth’ genoemd. eHealth kan kosteneffectief zijn, de communicatie met gezondheidswerkers vergemakkelijken en het welzijn verbeteren. Maar eHealth-benaderingen kunnen ook leiden tot praktische en ethische kwesties, bijvoorbeeld als de technologie niet relevant of bruikbaar is voor de oudere persoon. Daarom is een zorgvuldige evaluatie van een op technologie gebaseerde aanpak, zoals ESM, belangrijk.

Dit proefschrift heeft als doel inzicht in het dagelijks leven van ouderen uit verschillende doelgroepen te verkrijgen, met speciale aandacht voor cognitief en affectief functioneren en technologiegebruik. Een algemene inleiding met achtergrondinformatie, studieredenen, onderzoeksvragen en het proefschriftoverzicht is te vinden in **Hoofdstuk 1**.

Deel I richt zich op de haalbaarheid en bruikbaarheid van benaderingen en bevat een aantal methodologieën die informeren over verschillende aspecten van het dagelijks leven. De relatie tussen zelfrapportage en een observatietool die het vermogen beoordeelt om alledaagse technologie (AT) te gebruiken bij mensen met milde cognitieve stoornissen (MCI) ($n = 41$) of dementie in een vroeg stadium ($n = 38$) wordt bestudeerd in **Hoofdstuk 2**. De resultaten tonen aan dat mensen met dementie in een vroeg stadium in staat zijn om nauwkeurig na te denken over hun mogelijkheden om AT te gebruiken, maar beide methoden moeten worden gecombineerd om een alomvattend beeld te krijgen van technologiegebruik.

In **Hoofdstuk 3** wordt met deze aanbevelingen rekening gehouden om de haalbaarheid van ESM via smartphone te evalueren bij mensen met MCI. Een meerderheid van de deelnemers (n = 18) kan ESM goed gebruiken en reflecteert positief op de aanpak. Echter, een klein aantal deelnemers (n = 3) valt uit vanwege cognitieve problemen. Ook zijn veel gecontacteerde mensen met MCI niet in het bezit van smartphones, wat wijst op een beperkte algemene toepasbaarheid. De bruikbaarheid van momentane gegevens wordt aangetoond op groeps- en individueel niveau en onthult grote variabiliteit binnen en tussen proefpersonen.

Om cognitie op een objectieve manier in het dagelijks leven te beoordelen, worden tijdelijke cognitieve taken ontwikkeld om de verwerkingssnelheid (**Hoofdstuk 4 en 5**) en visueel-ruimtelijke geheugenfuncties (**Hoofdstuk 5**) te meten, en getest bij gezonde volwassenen om de haalbaarheid en validiteit te bepalen. Er is initieel bewijs geleverd voor de algemene haalbaarheid en contextuele validiteit, maar er wordt meer onderzoek voorgesteld om de taken te verbeteren.

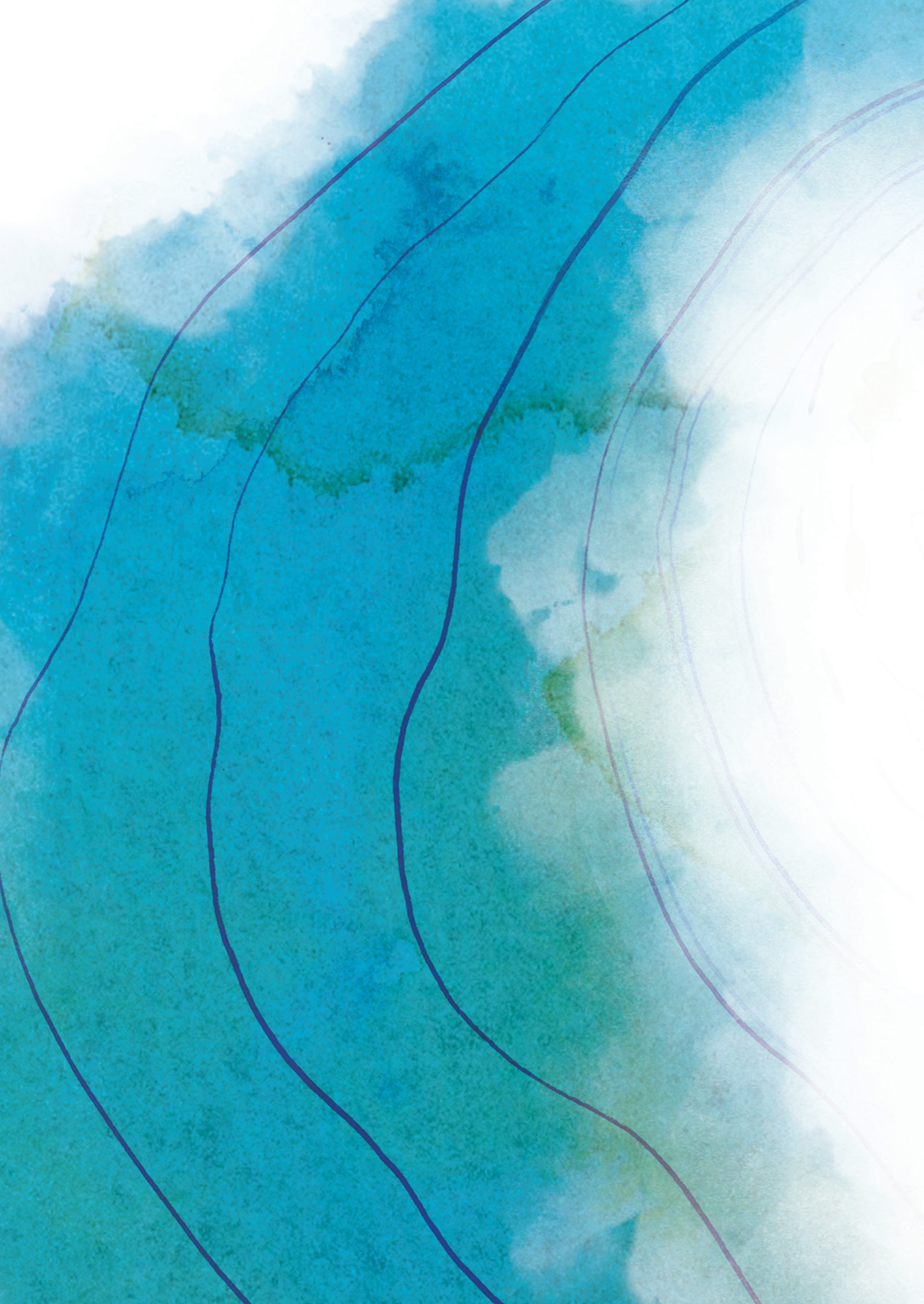
Deel II richt zich op het onderwerp *interventies en effectiviteit*. Er wordt een systematische review op basis van narratieve synthese uitgevoerd om een overzicht te geven van hoe digitale zelfmonitoring gebruikt kan worden in interventieopstellingen om de gezondheid van middelbare en oudere volwassenen te bevorderen (**Hoofdstuk 6**). De belangrijkste bevindingen benadrukken dat interventies sterk gericht zijn op volwassenen van middelbare leeftijd, en toekomstig gebruik moet zowel online als persoonlijke feedback bevatten, evenals sociale gezondheidselementen. Verder is er meer onderzoek nodig naar interventiemechanismen, de duurzaamheid van interventie-effecten en blijvende veranderingen in levensstijl.

Daarom worden de mechanismen van de op ESM-gebaseerde ‘Partner in Zicht’-interventie voor partner van mensen met dementie bestudeerd in **Hoofdstuk 7**. Dit project maakt gebruik van momentane gegevens die tijdens de interventie zijn verzameld en richt zich op veranderingen in de dagelijkse activiteiten van de mantelzorger en op hun verband met affect en activiteits-gerelateerde stress. De resultaten tonen aan dat alleen verzorgers die ESM gebruiken en ook gepersonaliseerde feedback ontvangen, hun gedrag veranderen, namelijk door meer deel te nemen aan passieve ontspanningsactiviteiten. Deze verandering hangt echter samen met gemengde emoties.

De duurzaamheid van positieve effecten op het welzijn van de mantelzorger als gevolg van deze interventie wordt ook na zes maanden geëvalueerd (**Hoofdstuk 8**). Helaas vervagen positieve interventie-effecten en moeten toekomstige interventies mogelijk aanvullende functies bevatten. Zo kunnen micro-interventies of boostersessies worden overwogen.

In **Deel III** worden aspecten van de implementatie van interventies verkend door middel van een systematische review die zich richt op eHealth-interventies voor mantelzorgers van mensen met dementie (**Hoofdstuk 9**). De bevindingen tonen aan dat de meeste studies zich concentreren op de kenmerken van de eHealth-interventie zelf en van de mantelzorgers, terwijl het organisatieniveau en de bredere context weinig aandacht krijgen. Toekomstige studies moeten de kloof tussen onderzoek en praktijk overbruggen.

Hoofdstuk 10 bespreekt de belangrijkste bevindingen, benadrukt methodologische en conceptuele overwegingen, klinische implicaties en aanwijzingen voor toekomstig onderzoek.



Addendum

Sammanfattning

Sammanfattning

Med åldern ökar risken för att en individ måste anpassa sig till ett liv med kognitiva nedsättningar eller demens, antingen för att man själv drabbas eller för att en anhörig drabbas och behöver daglig hjälp. Dessa förändringar i vardagen kan vara utmanande och komplexa, därför är det viktigt för forskare och vårdpersonal att förstå individens situation och behov så väl som möjligt för att kunna tillhandahålla ett gott stöd.

Det finns olika metoder för att få insikt i individers dagliga aktivitetsmönster och hälsa exempelvis via självskattningsformulär, rapportering från anhöriga, eller neuropsykologiska bedömningar och observationer av forskare/vårdpersonal. Även om många metoder är valida, har god reliabilitet och är allmänt användbara, har de sina begränsningar. Till exempel förlitar sig självskattningsformulär på ett gott minne och neuropsykologiska bedömningar sker i lugna, onaturliga kliniska miljöer. En metod som däremot kan samla detaljerad information i ögonblick när något sker, är erfarenhetsinsamling via en dagboksmetod.

Erfarenhetsinsamling (English: Experience Sampling Method) är en innovativ, teknikbaserad dagboksmetod som för närvarande sällan används i populationer med äldre personer. Erfarenhetsinsamling gör det möjligt för individer att rapportera om sina känslor och beteenden, samt kontext, i vardagliga situationer. Att använda teknik, som en digital dagbok, syftar till att förbättra hälsan och kallas e-hälsa. E-hälsa kan vara en kostnadseffektiv metod som stödjer kommunikation mellan användaren och vårdpersonalen samt bidrar till att öka välbefinnande hos målgruppen. Dock kan interventioner med e-hälsa härledas av praktiska och etiska frågor, till exempel om tekniken är relevant för eller användbar av den äldre personen. Därför är det viktigt att utvärdera tillvägagångssättet med en erfarenhetsbaserad metod som inkluderar teknik.

Denna avhandling syftar till att öka förståelsen om vardagen för äldre personer i olika målgrupper med särskilt fokus på deras kognitiva och affektiva funktioner samt hur de använder teknik. I **Kapitel 1** presenteras en allmän introduktion innehållande bakgrundsinformation, studierationaliseringar, forskningsfrågor och avhandlingens upplägg.

Del I av avhandlingen fokuserar på genomförbarheten och användbarheten av olika metoder som kan informera om olika aspekter av vardagen. I **Kapitel 2** beskrivs förhållandet mellan ett självskattningsformulär och ett observationsverktyg som båda bedömer förmågan att använda vardagsteknik hos personer med en mild kognitiv nedsättning (MCI) (n = 41) eller tidig demens (n = 38). Resultaten påvisar att personer med tidig demens har möjlighet att tillhandahålla tillförlitliga reflektioner över sina förmågor att använda vardagsteknologi, men att båda metoderna bör kombineras för att få en mer komplett bild av teknikanvändningen.

I **Kapitel 3** beaktas rekommendationerna från kapitel 2 för att utvärdera genomförbarheten av en erfarenhetsinsamling med smarttelefoner för personer som har MCI. För en majoritet av deltagarna (n = 18) fungerade erfarenhetsinsamlingsmetoden bra och de var positiva till tillvägagångssättet. Ett mindre antal deltagare (n = 3) avbröt sitt deltagande på grund av sina kognitiva problem. Svårigheter var även att många personer med MCI som blev kontaktade för studien inte ägde smarttelefoner, vilket indikerar en begränsad allmäntillämpning. Användbarheten av data som tillhandahölls via dagboken presenteras på grupp- och individnivå, vilket påvisar stora variationer mellan deltagarna.

För att bedöma kognition på ett mer objektivt sätt i vardagen har ett kognitionstest, baserat på dagboksmetoden, utvecklats för att mäta processhastighet (**Kapitel 4 & 5**) och visuospatiala minnesfunktioner (**Kapitel 5**). Testet har genomförts med vuxna i medelåldern, för att utvärdera genomförbarheten och reliabiliteten. Initiala resultat indikerar en möjlig genomförbarhet och valid kontext, men mer forskning är önskvärd för att vidareutveckla testet.

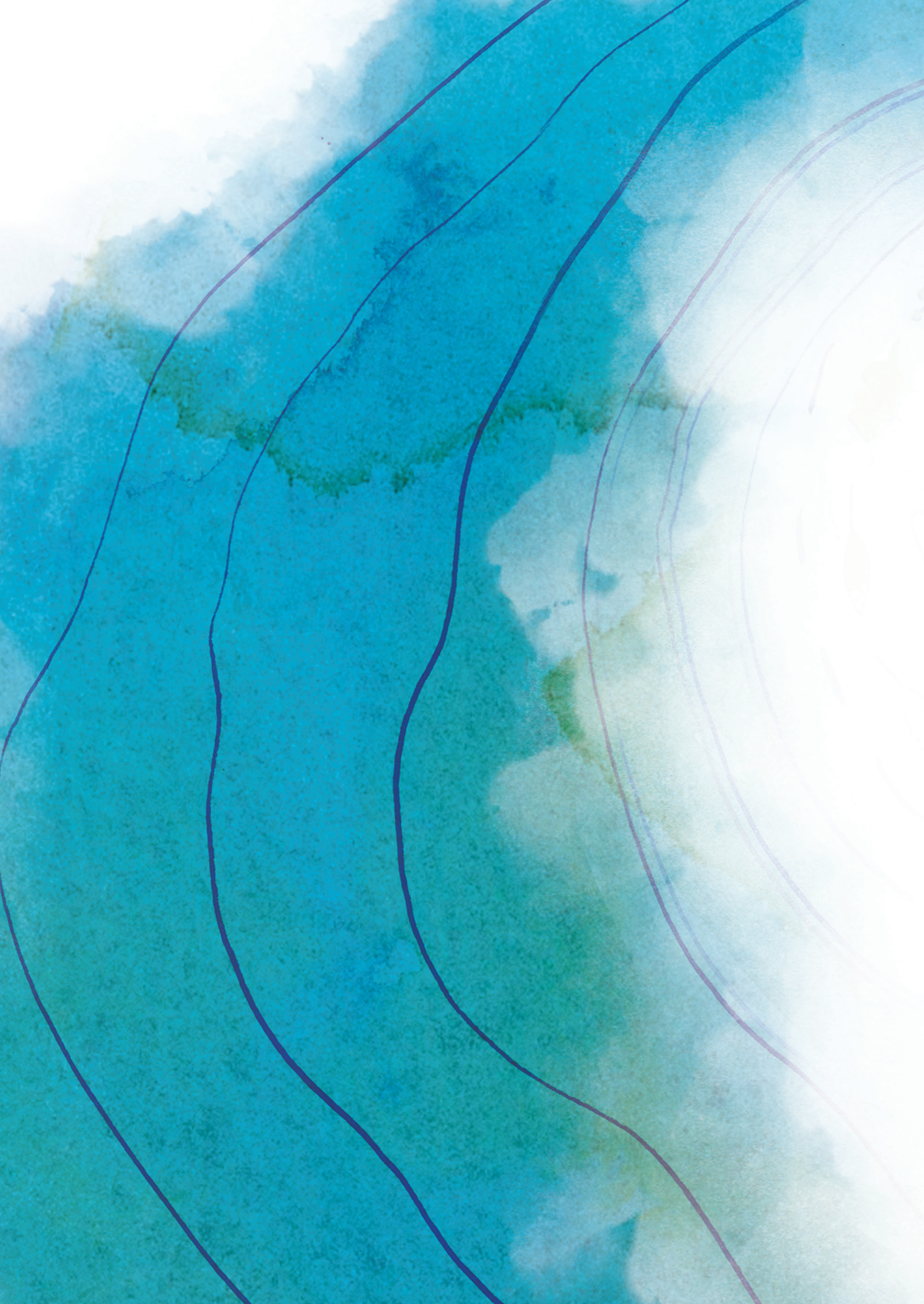
Del II fokuserar på interventioner och effektivitet. En narrativ sammanfattning av en systematisk översiktsgranskning genomförs för att generera en bild över hur digital självmonitorering kan användas i interventioner för att främja hälsa hos vuxna personer (**Kapitel 6**). Resultatet påvisar att interventionerna har ett stort fokus på vuxna i medelåldern och att framtida interventioner bör inkludera återkoppling som sker både fysiskt och online samt innehåller sociala hälsoaspekter. Vidare behövs mer forskning för att förstå mekanismerna i interventionen, de långsiktigt hållbara effekterna av interventionen samt hur varaktiga livsstilsförändringar är.

I interventionsstudien ”Partner in Sight” studeras mekanismerna av en erfarenhetsbaserad intervention, där makar till personer med demens deltar (**Kapitel 7)**. Där används dagboksdata som samlas in under hela interventionen med fokus på förändringar som sker i den anhöriges dagliga aktiviteter samt om dessa aktivitetsförändringar har samband med affektiv- och aktivitetsrelaterad stress. Resultaten visar att det endast är de anhöriga som använder en erfarenhetsbaserad metod i kombination med personlig fysisk återkoppling som ändrar sitt beteende på grund av att de engagera sig mer i passiva avslappningsaktiviteter. Denna förändring generar dock blandade känslor hos de anhöriga.

Hållbarheten av de positiva förändringarna av den anhöriges välbefinnande efter deltagande i ”Partner in Sight” interventionen, utvärderas efter sex månader (**Kapitel 8**). Tyvärr verkar de positiva effekterna minska över tid, därmed kan ytterligare funktioner i interventionen behöva läggas till i framtiden som till exempel mikrointerventioner eller boosting sessioner.

I **Del III** presenteras en systematisk översikt gällande implementering av e-hälsointerventioner för anhöriga som vårdar personer med demens (**Kapitel 9**). Resultaten visar att de flesta studier koncentrerar sig på e-hälsoapplikationen och egenskaper hos de anhöriga vårdarna, medan lite uppmärksamhet tillägnas organisationsperspektivet och den större kontexten. Därmed bör framtida studier fokusera på att minska kunskapsluckan mellan forskning och praktik.

I Kapitel 10 diskuteras de viktigaste resultaten, de metodologiska och konceptuella överväganden, kliniska implikationer och anvisningar för framtida forskning.



Addendum

Knowledge valorisation

Knowledge valorisation

The main aim of this thesis is to improve the understanding of everyday life in older adults of different target groups with a special focus on cognitive and affective functioning and technology use. The following valorisation addendum elaborates on the societal relevance and value that the obtained knowledge resulting from this dissertation may have.

Societal relevance

We live in an aging society and humans are now getting older than ever before. With older age, the risk to develop cognitive impairments and dementia increases. Currently, 50 million people are living with dementia worldwide and the number is expected to triple by 2050. Dementia has a physical, psychological, societal, and economic impact on the person with dementia, their family, and wider society. Due to the lack of curative treatment, attention needs to be paid to the day-to-day care and support, as well as prevention. To provide the best support possible, it is crucial to understand the complexity of everyday life, individual needs, and unique situations. As traditional methods assessing aspects of a person's life rely on memory recall and often neglect fluctuations or contexts, it seems necessary to consider and promote applying new strategies.

The Experience Sampling Method (ESM), a digital diary approach and the key method of this dissertation, allows individuals and health care professionals to gain a more fine-graded picture of daily patterns. To improve coping, the momentary information can be reviewed together with a health care professional identifying activities and behaviours that elicit happiness or that are perceived as particularly stressful. It can also provide information on the frequency and severity of cognitive problems in context.

This thesis provides evidence on the feasibility and usability of the ESM in people with mild cognitive impairment (MCI), as well as information on relevant intervention elements such as personalised feedback following a blended care principle to support older adults including carers of people with dementia. The results also highlight the need to be aware that not all older adults will be able to or interested in using a technology-based approach, and therefore, eHealth in general should not be the only option. Nevertheless, digital self-monitoring such as the ESM holds promise to improve the understand and promotion of various health aspects in different aging populations.

Target audience

The results described in this dissertation are relevant for people with MCI, dementia, family carers, health care professionals, researchers, and policy makers.

People with MCI have an increased risk to deteriorate to dementia. Therefore, it is important to support self-management and coping when dealing with MCI to minimize the risks of cognitive decline. Evidence exists that not only cognitive or physical trainings, but also social activities and the management of depression can contribute to a reduced risk of deterioration. This dissertation highlights the need to approach health as a complex, multi-layered construct and to ensure that interventions incorporate all health aspects. Digital self-monitoring interventions using the ESM may prospectively be a useful tool to support self-management in people with MCI. In the future, researchers and health care professionals may explore the use of digital self-monitoring interventions to improve health and prevent cognitive decline in people with MCI further.

Just like people with MCI, also people with dementia need to be included in the research process. Participating in research ensures not only that the individual's wishes and needs are heard, but can also stimulate feelings of empowerment and meaning. This dissertation shows that people in early stages of dementia are able to accurately reflect on their ability to use everyday technology. When developing or testing eHealth solutions, the input from people with dementia should therefore be included early on.

This dissertation also extends the knowledge on how ESM-based interventions affect family carers. While an ESM intervention may result in increased emotional well-being, regular and personalized feedback needs to be included to stimulate a behavioural change towards more activities that elicit positive emotions as well. Additionally, family carers need long-term support and booster sessions or micro-interventions are suggested to maintain intervention effects. When looking at the implementation of eHealth interventions for family carers, the gap between research and practice needs to be closed to facilitate a sustainable use.

Health care professionals and researchers may use eHealth such as the ESM more in the future as it allows to understand the daily challenges of older adults in a more detailed way. This dissertations also demonstrates the usability of momentary data, recommends to discuss results in feedback session together with the clients, and promotes health as a complex, multi-layered concept. Health care professionals may want to reflect critically on their currently used methods to understand help-seeking individuals and the ESM can be an interesting addition to their 'toolbox'.

Finally, to promote the implementation and sustainable use, policy makers should be engaged in the research process just like users early on. Their views and influence may contribute to a successful translation from academia into practice. eHealth and the ESM can prospectively be beneficial to maintain or improve affective and cognitive functioning in older adults and all stakeholders need to understand and facilitate these advantages.

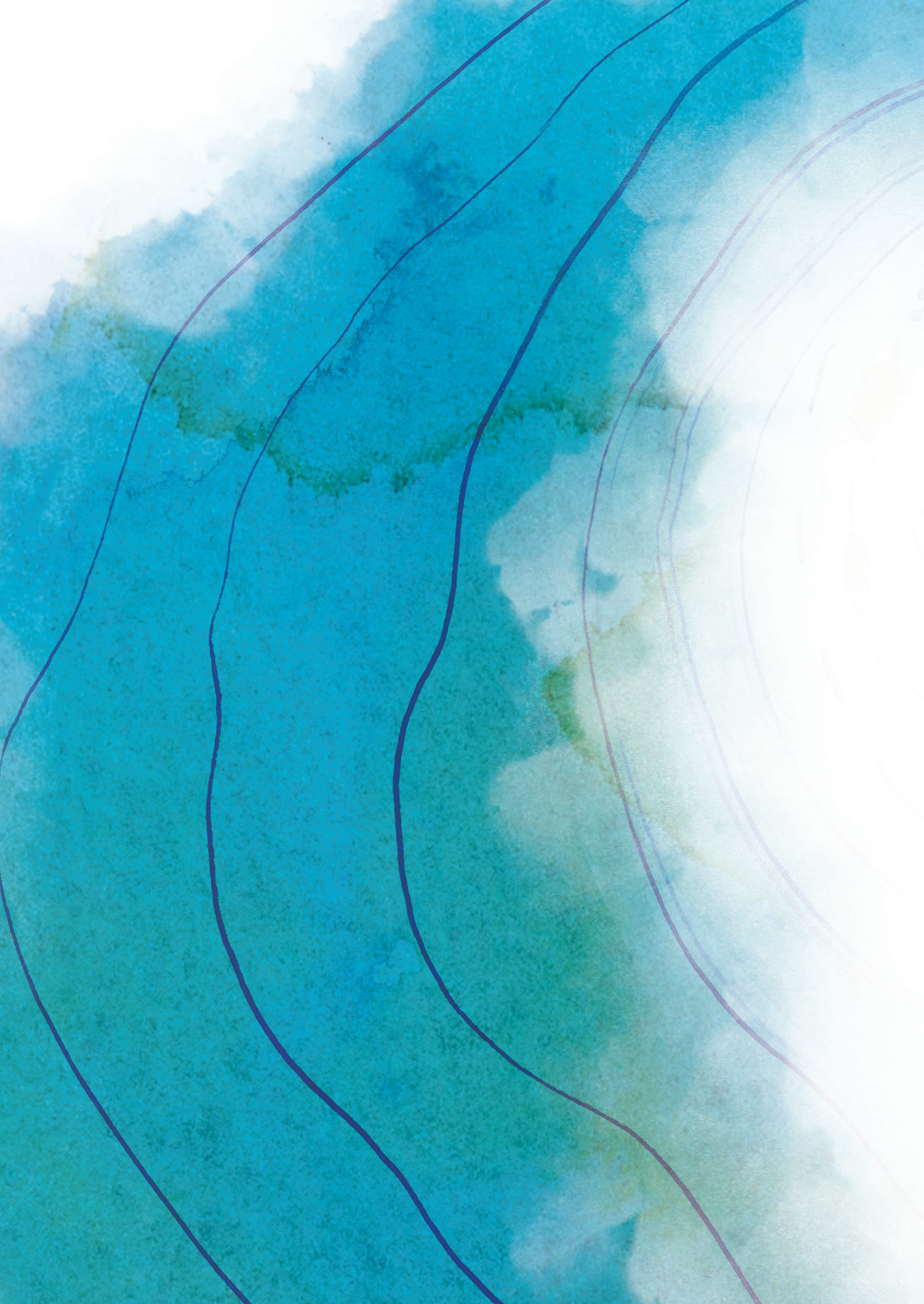
Innovation and implementation

The ESM is rarely applied in aging populations as the use so far focusses mainly on middle-aged or younger adults. To our knowledge, this dissertation is the first to test smartphone-based ESM in an MCI population. The mostly positive results of the feasibility of the ESM in MCI may encourage other researchers and clinicians to make use of this methodology in research and health care.

Furthermore, the studies presented in this dissertation advance the use of the ‘PsyMate’ app through the development and evaluation of two momentary cognition tasks. Particularly the momentary Digit Symbol Substitution Task shows to be a reliable tool to study daily cognitive functioning. The ‘PsyMate’ app is already implemented into several Dutch health care facilities and the momentary cognition tasks could prospectively be used in mental and neurological patient populations to study cognition in everyday life.

Using momentary data to understand intervention mechanisms and daily changes over the course of an intervention is also rarely done, as randomized controlled trials seem to be the golden standard to evaluate interventions. However, studying mechanisms in such a way allows to open the black box of everyday life and informs on the processes that get leveraged by intervening in a complex system. Similarly, narratively synthesising intervention elements can help our understanding of the design and elements that could be considered for future interventions. This dissertation therefore provides useful evidence for the set-up of prospective ESM-based interventions.

To disseminate the results from this thesis, we present our findings to academic and lay audiences on a national as well as international level. Inter-sectorial and interdisciplinary collaborations also contribute to the circulation of the achieved knowledge. Finally, a motion graphic will be available shortly summarizing and illustrating the key findings in an understandable way. The researchers involved in this dissertation aim to promote the use of the ESM in research and clinical practice in their future work.



Addendum

Publications and Presentations

Publications and Presentations

International publications in peer-reviewed journals

2020

- **Bartels, S.L**., Van Knippenberg, R.J.M., Malinowsky, C., Verhey, F.R.J., & De Vugt, M.E. (Accepted). Smartphone-based Experience Sampling in People with Mild Cognitive Impairment: A Feasibility and Usability Study. JMIR: Aging.
- Stayaert, J., Deckers, K., Smits, C., Fox, C., Thyrian, R., Jeon, Y.-H., Vernooij-Dassen, M., Koehler, S., on behalf of the Interdem taskforce on prevention of dementia (2020). Putting primary presention of dementia on everybody's agenda. Aging & Mental Health.
- Daniëls, N. E. M./ **Bartels, S. L**., Verhagen, S. J. W., Van Knippenberg, R. J. M., De Vugt, M. E., & Delespaul, P. A. (2020). Digital assessment of working memory and processing speed in everyday life: Feasibility, validation, and lessons-learned. Internet Interventions, 19, 100300.

2019

- Verhagen SJW/ Daniëls NEM, **Bartels** SL, Tans S, Borkelmans KWH, de Vugt ME, et al. (2019) Measuring within-day cognitive performance using the experience sampling method: A pilot study in a healthy population. PLoS ONE 14(12): e0226409.
- **Bartels,** S. L., Van Knippenberg, R. J. M., Dassen, F. C. M., Asaba, E., Patomella A.-H., Malinowsky, C., Verhey, F. R. J. & De Vugt, M. E. (2019) A Narrative Synthesis Systematic Review of Digital Self-Monitoring Interventions for Middle-Aged and Older Adults. Internet Interventions.
- **Bartels,** S. L., Assander, S. , Patomella, A.-H., Jamnadas-Khoda J. & Malinowsky, C. (2019): Do you observe what I perceive? The relationship between two perspectives on the ability of people with cognitive impairments to use everyday technology, Aging & Mental Health.
- **Bartels**, S. L., van Knippenberg, R. J. M., Köhler, S., Ponds, R.W., Myin-Germeys, I., Verhey, F. R. J. & de Vugt, M. E. (2019): The necessity for sustainable intervention effects: lessons-learned from an experience sampling intervention for spousal carers of people with dementia, Aging & Mental Health.

2018

- Christie, H.L., **Bartels,** S.L., Boots, L.M., Tange, H.J., Verhey, F.J., & de Vugt, M.E. (2018). A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. Internet interventions.
- Ahmed, S., Loane, C., **Bartels**, S., Zamboni, G., Mackay, C., Baker, I., Husain, M., Thompson, S., Hornberger, M., & Butler, C. (2018). Lateral parietal contributions to memory impairment in posterior cortical atrophy. NeuroImage: Clinical

A

Submitted articles

- **Bartels**, S.L., Van Knippenberg, R.J.M., Viechtbauer, W., Simons, C.J.P., Ponds, R.W., Myin-Germeys, I., Verhey, F., & De Vugt, M.E. (submitted; this thesis). Intervention Mechanisms of an Experience Sampling Intervention for Spousal Carers of People with Dementia: A secondary Analysis using momentary Data

Scientific communication and outreach related to this thesis

2020

Written contribution for MHeNs website (Online)
Invited speaker, oral presentation at the INTERDEM Academy Masterclass "Social Cognition & Technology in Dementia" (Online)

2019

Poster pitch at the Advances in Health Care Science Conference (Stockholm, Sweden)
E-Pitch at MHeNs research day (Maastricht, the Netherlands)
Presentation at 5th INDUCT School (London, the United Kingdom)
Oral presentation at the 7th International Conference on Emotions, (Tilburg, the Netherlands)
Poster presentation at the 3rd ESM Expert Network Meeting, (Tilburg, The Netherlands)
Oral presentation at the 29th Alzheimer Europe Conference (The Hague, the Netherlands)
Oral presentation at KIREUM workshop/ collaboration meeting between Kobe University and Karolinska Institutet (Stockholm, Sweden)

2018

Written piece for INDUCT newsletter Fall 2018 (online)
Poster presentations at the 28th Alzheimer Europe Conference (Barcelona, Spain)
Presentation at 4th INDUCT School (Prague, Czech Republic)
Poster presentation at Symposium 'Neurofeedback and other Neuro-Technologies in Psychiatry' (Maastricht, the Netherlands)
Poster presentation at the 33rd International Conference of Alzheimer's Disease International (Chicago, USA)
Written piece for Alzheimer Limburg Website on 'Monitor-Mi Study' (online)
Written piece for INDUCT newsletter Spring 2018 (online)
Presentation at 3rd INDUCT School (Witten, Germany)

2017

Oral pitch at MHeNs Research Day (Maastricht, the Netherlands)

Poster presentation at 2nd INDUCT School (Salamanca, Spain)

Poster pitch at Advances in Health Care Sciences Conference (Stockholm, Sweden)

Poster presentation at the 27th Alzheimer Europe Conference (Berlin, Germany)

Oral pitch at the 32nd International Conference of Alzheimer's Disease International (Kyoto, Japan)

Written piece for Alzheimer Centrum Limburg newsletter (online)

Network blog for Wold Young Leaders of Dementia (WYLD), Interdem masterclass (online)

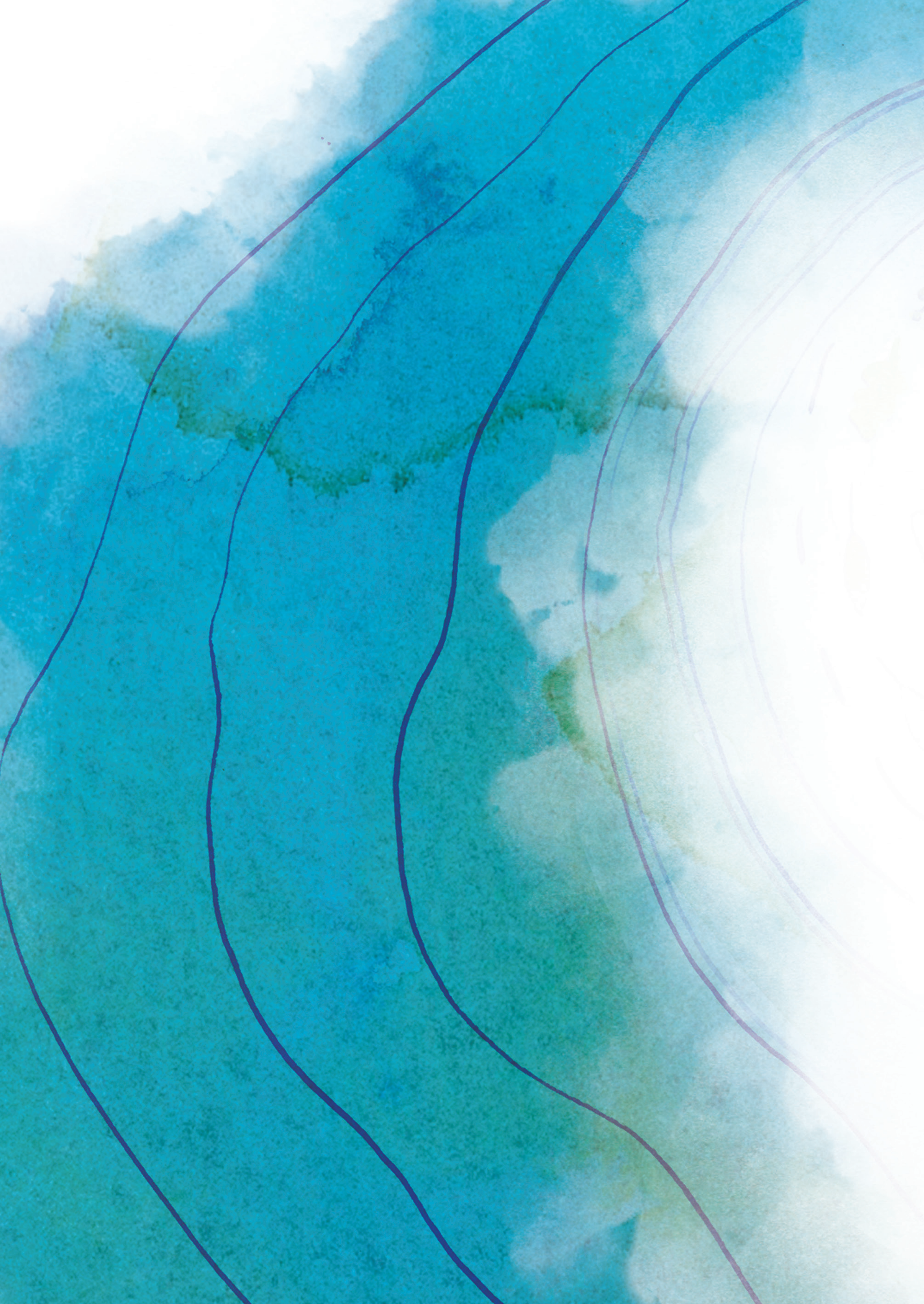
Pitch at 1st INDUCT School (Maastricht, the Netherlands)

2016

Written piece for INDUCT newsletter Winter 2016 (online)

Other

Regular posts on social media including Twitter (@SaraLBartels), LinkedIn, and Facebook



Addendum

Acknowledgements

Acknowledgements

Many people supported me in the last four years and thus contributed to me successfully completing this academic work. I would like to thank a couple of you especially:

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My **INDUCT** family also contributed to my personal and professional growth. Thank you, **Martin O.,** for seeing my potential as a researcher early on and all the enjoyable conversations we had over the years. Big thanks to **Deborah, Orii**, and **Inge K.** for organising beautiful schools and events all over Europe! Thanks to **Fania** for such a fabulous job within INDUCT as well as our collaboration on Chapter 6. You are a great listener and our conversations always calmed me down somehow. **Lucas**, thank you for showing me the business world during my secondment at Eumedianet – I enjoyed the talks we had at the schools or the rides to the care homes! To all my **fellow ESRs** – we can be very proud of ourselves for managing the projects, our lives, and all the INDUCT requirements over the years (especially the 147682374 tertial reports!). I felt understood and safe with you, thank you! I wish all of you the very best and hope our paths cross again in the future!

To all my dear colleagues from the **Department of Psychiatry and Neuropsychology and Alzheimer Centrum Limburg**, thank you for so many nice interactions over the last years. I will miss your smiles on the hallways just as much as the mingle days or the heidag. Special thanks goes to the following of you: **Hannah,** the question ‘Are you also here for the INDUCT interview event?’ was the start of our journey together as PhD students in Maastricht. Living in our

place at Maadgendries (and buying our first sofas together), traveling Europe, Asia, and the U.S. (or missing a flight in Copenhagen), taking pictures of each other being excited about awesome meals, having meltdowns over boys or life, listening and helping each other out wherever needed (including but not limited to English editorial duties or borrowing cloths)... It was a true pleasure to spend those crazy years with you! Thanks for being there for me– we were put together by 'mum and dad' and I am happy that you became my PhD sister. **Angelique,** you are just as nerdy as me – actually probably nerdier, but in the best way possible ♥ and I love it! Our walks and talks, game or movie nights, being one of your bridesmaids, cheering each other on, and celebrating our achievements. Thank you for being a wonderful colleague and dear friend. **Mignon**, I wish we would have spent more time together earlier, as every time we met, I just left with a smile on my face (and a sore body after a good workout!). I trust you and you always find the right words. Thanks for being you and supporting me in Maastricht and beyong. **Nikos,** walks through Maastricht and beers on the city wall – one of my favourite things to do! Or rather Whiskey at the Irish pub? I found a friend in you and are thankful for that. I am already looking forward to hanging out in Amsterdam soon! **Linda**, thinking about the beginning when we were roomies, our lunch breaks at Banditos, or the late-night conversation that we had after Simone's defence just makes me smile. I love your style (probably said 'nice outfit' 100 times haha) and enjoy being around you ☺. **Olin**, thank you for intense fitness session at UM sports together, visiting 'paradise' in Sweden with me, or a fun memory seeing Tove Lo in Cologne with the girls, where **Leonie** also joined. To you, Leonie, thanks for always trying to teach me Dutch and not switching to English right away ;), for some nice cooking evenings and a good memory being together at Maastricht Christmas market. **Niels,** es war immer schön Deutsch mit dir zu sprechen. Danke für deine Statistik Tipps, dein freundliches Lächeln, und bleib so wie du bist! **Lisa**, deine positive und entspannte Art hat mich immer etwas beruhigt und ich habe die Kaffeepausen bei Banditos sehr genossen. Dir und deiner Familie alles Liebe! **Roos,** I would not know where I would be without you! You supported me so much, have a big heart, and the participants love you too. Without you, Chapter 3 would be non-existing ;). Thank you very, very much! **Astrid,** thanks for always speaking Dutch to me – I could finally practice a bit – and your great support with the recruitment. **Vienna,** you also supported the recruitment quite a bit and I enjoyed testing participants with you very much. Thank you! **Danielle and Els**, thank you for arranging meetings and helping with any kind of admin questions I could have. You always know the answer to any question! **Ron M**., the answer to my technical problem was mostly that the Cisco connection was not running or I had forgotten my password – but you helped me anyway with a smile. Thank you! **Bert and Rudolf**, thank you for sharing your ESM expertise with me and Simone! Thank you all! **Golnaz**, it is a great pleasure to support you with your research and I want to thank you for trusting me with questions and opening up to me. I am looking forward to many more brainstorm meetings and skypes with you! **Anouk,** even though our office hours only overlapped here and there, I thank you for friendly office conversations and wish you all the best. **Inge,** pick nick and rain at the Maas, dinner at the foodbank, or zoom drinks! I enjoyed hanging out with you, thank you and all the best!

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Thank you to the **Division of Occupational Therapy at the Karolinska Institutet** for hosting me in 2017 and letting me join your department in 2019 ones more. Special thanks goes to **Louise, Sarah, Sophie, Eric, Ann-Helen, Sussi, and Liv** ☺ for many Fikas, a fun division run, interesting meetings, and educating me about occupational therapy and ET use!

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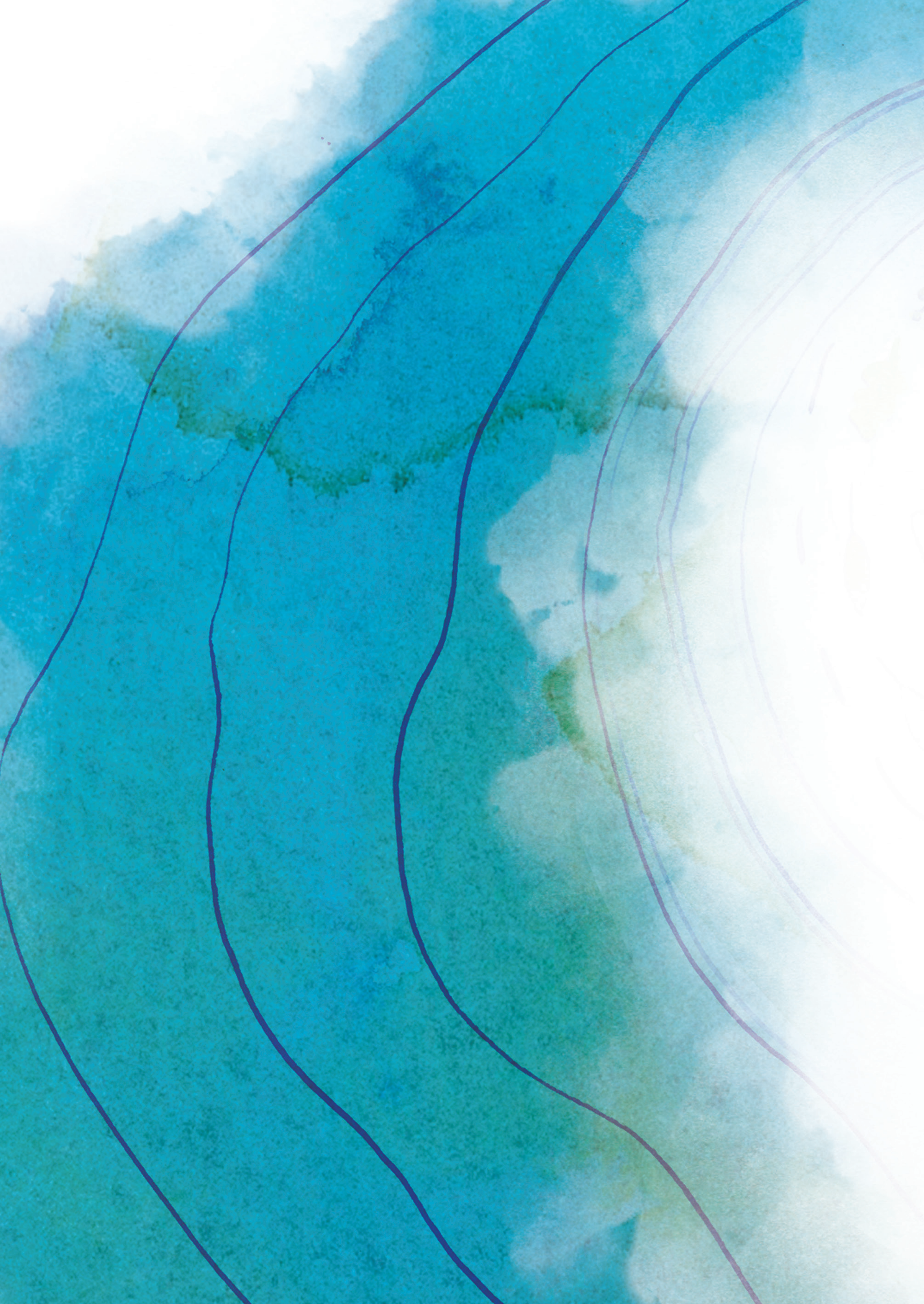

Addendum

Thesis defences from MHeNs –
School for Mental Health and Neuroscience

Thesis defences from MHeNs – School for Mental Health and Neuroscience

2019

Jans van Ool. **Diagnostic and neuropsychiatric considerations in epilepsy and intellectual disability; Psychological perspectives.** Supervisor: Prof.dr. A. Aldenkamp. Co-supervisors: Dr. J. Hendriksen; Dr. H. Schelhaas, Kempenhaeghe.

Eveline Janssen. **Depression in the elderly: focus on high risk groups.** Supervisors: Prof.dr. F. Verhey; Prof.dr. M. de Vugt. Co-supervisor: Dr. M. Schram.

Cécile Kicken. **Extreme blood coagulation; investigating the influence of physiological extremes on thrombin generation and platelet activation.** Supervisor: Prof.dr. W. Buhre Co-supervisors; Dr. B. de Laat; Dr. M. Lancé, Qatar.

Martinus van Eerd. **Diagnosis and Interventional Pain Treatment of Cervical Facet Joint Pain.** Supervisor: Prof.dr. M. van Kleef. Co-supervisor; Dr. J. Patijn, Eindhoven; Dr. M. Sommer.

Chenxing E. Zhang. **Novel insights in the pathophysiology of cerebralsmall vessel disease – a study using advanced imaging techniques.** Supervisors: Prof.dr. R.J. van Oostenbrugge; Prof. dr.ir. W.H. Backes; Co-supervisor: dr. J. Staals.

Ivo Eijkenboom. **A zebrafish model of small-fiber neuropathy.** Supervisors: Prof.dr. H.J.M. Smeets; Prof.dr. C.G. Faber; Co-supervisor: dr. J. Vanoevelen.

Bianca de Greef. **Small fiber neuropathy: from underlying conditions to treatment.** Supervisor: Prof.dr. C.A. Faber; Co-supervisor: Dr. I.S.J. Merkies; Dr. J.G.J. Hoeijmakers.

Lotte Berk. **MINDFULNESS AND AGING: Exploring Mechanisms and Interventions.** Supervisors: Prof.dr. J. van Os; Prof.dr. M.W. de Vugt; Co-supervisor: dr. M.P.J. van Boxtel.

Mor Dickman. **Practice patterns and outcomes of corneal transplantation.** Supervisor: Prof. dr. R.M.M.A. Nuijts; Co-supervisors: Dr. T.J.M. Berendschot; dr. F.J.H.M. van den Biggelaar.

Thyagi Ponnamperuma. **Mental Health Problems in Sri Lankan Adolescents Exposed to the Tsunami and Other Traumatic Events.** Supervisor: Prof.dr. M.W. De Vries; Co-supervisor: Dr. N.A. Nicolson.

Robbert C. Maatman. **Anterior cutaneous nerve entrapment syndrome (acnes): an analysis of various subtypes and alternative treatment modalities.** Supervisor: Prof.dr. M. van Kleef; Co-supervisors: Dr. R.M.H. Roumen, dr. M.R.M. Scheltinga.

Mari Elshout. **Neovascular Age-Related Macular Degeneration in the Era of Value-Based Health Care.** Supervisor: Prof.dr. C.A.B. Webers; Co-supervisor: Dr. J.S.A.G. Schouten.

Jeroen Deenik. **Thinking inside the box; Changing lifestyle to improve the health status of inpatients with severe mental illness.** Supervisor: Prof.dr. P.N. Harten; Co-supervisors: Dr. D.E. Tenback; dr. I.J.M. Hendriksen.

Thomas Draak. **Peripheral Neuropathy outcome measures Standardisation (PeriNomS) study part 3: Capturing the Patient's Voice.** Supervisor: Prof. dr. C.G. Faber; Co-supervisor: Dr. I.S.J. Merkies.

Ana Luisa Gil Martínez. **Neuroprotection in neurodegenerative processes associated with Parkinsonism and aging. Correlation between dopaminergic neuronal death and glial activation.** Supervisor: Prof.dr. H.W.M. Steinbusch, Prof.dr. Maria-Trinidad Herrero Ezquerro, University of Murcia.

Bernice J.A. Gulpers. **Anxiety in older adults; Correlates, comorbidities and prognosis with lifespan perspectives**. Supervisor: Prof.dr. F.R.J. Verhey, Prof.dr. R.C. Oude Voshaar; Co-supervisor: Dr. S. Köhler.

Elke Devocht. **Combining a cochlear implant and a hearing aid in opposite ears: The best of both worlds.** Supervisor: prof.dr. H. Kingma; co-supervisor: dr. E.I.J. George.

Gillian Townend**. Rett Syndrome: Recognising the Communication Challenges, Needs and Potential of Individuals Living with a Rare Disease.** Supervisor: Prof.dr. L.M.G. Curfs; co- supervisor: Dr. P.B. Marschik, Med. University of Graz, Austria.

Takashi Koizumi. **Genetic and neuroinflammatory components of familial and sporadic cerebral Small Vessel Disease.** Supervisor: Prof.dr. H. Steinbusch,Prof.dr. T. Mizuno,Japan; co-supervisor: Dr. S. Foulquier.

Muhammad Ali. **Integrative network-based approaches for modelling Human disease**. Supervisor: Prof.dr. J. Kleinjans; co-supervisor: Dr. D. van den Hove; Dr. E. Pishva.

Guillaume Durand. **The adaptive side of psychopathy. Investigating adaptive characteristics associated with the psychopathic personality**. Supervisor: Prof.dr. B. Rutten; co-supervisor: Dr J. Lobbestael.

Darius C. Henatsch. **Honey: A Novel Treatment in Chronic Ear Infections**. Supervisor: Prof.dr. R.J. Stokroos; UMC Utrecht/UM; co-supervisor: Dr. J.J. Briedé.

Reinhilde J. Melles. **Vaginal penetration: pain or pleasure? The role of fear and sexual arousal**. Supervisor: Prof.dr. M.L. Peters; co-supervisor: Dr. M. ter Kuile, LUMC, Dr. M. Dewitte.

Raul Felipe Abella Antón. **Cardiac Surgery Biochemical Monitoring in Congenital Heart Diseases Infants.** Supervisors: Prof. dr. D. Gazzolo, Prof. dr. L.J.I. Zimmermann, Prof. dr. J.S.H. Vles, co-supervisor; Dr. A.W.D. Gavilanes.

Francesca M. Snoeijen-Schouwenaars. **Diagnostic, neuropsychiatric and therapeutic considerations in epilepsy and intellectual disability – medical perspectives –.** Supervisor: prof.dr. A.P. Aldenkamp, co-supervisors: Dr. H.J. Schelhaas, SEIN Zwolle; dr. J.G.M. Hendriksen, Kempenhaeghe, Heeze.

Mariëlle H.J. Pruppers. **Peripheral Neuropathies: Standardizing Functional Assessment.** Supervisors: prof.dr. C.G. Faber; prof.dr. N.C. Notermans, UU;Dr. I.S.J. Merkies, ius promovendi.

Shenghua Zong. **Autoantibodies in disorders of the brain: expanding the spectrum.** Supervisor: prof.dr. P. Marinez; co-supervisor: dr. M. Losen; dr. R. Rouhl.

Jan-Willem Kallewaard. **Diagnosis and minimally invasive treatment of chronic discogenic low back pain.** Supervisor: prof.dr. M. van Kleef; co-supervisors: prof.dr. H. van Santbrink; dr. P. Willems.

Simone M. Crivelli. **Sphingolipid metabolism in the pathophysiology and treatment of Alzheimer's disease.** Supervisors: prof.dr. P. Martinez-Martinez; prof.dr. E. de Vries, VUmc. Co-supervisors: dr. M. Losen; dr. M. Mulder, Rotterdam.

Natasha Pahuja. **Etiopathogenesis, advanced imaging and treatment outcomes in Asian Indians with keratoconus.** Supervisor: prof.dr. R. Nuijts, co-supervisor: dr. R. Shetty, Bengaluru.

Pooja Khamar Mayur Raksha. **Clinical, Molecular and Biomechanical outcomes of SMILE (small incision lenticule extraction) and other refractive surgery techniques.** Supervisor: prof.dr. R. Nuijts, co-supervisor: dr. R. Shetty, Bengaluru.

Niels Janssen. **Patterns and pathways. Indicators for potential improvements of dementia care.** Supervisors: prof.dr. F. Verhey; prof.dr.mr. S. Evers; Co-supervisor: dr. R. Handels.

Giovanni Mansueto. **Childhood adversities and Psychosis: investigation of the potential aetio-pathogenetic mechanisms.** Supervisor: prof.dr. K. Schruers; co-supervisors: prof.dr. F. Cosci, University of Florence, It; prof.dr. R. van Winkel, KU Leuven.

Joke Debruyne. **Cochlear implantation in adults with early-onset deafness.** Supervisors: prof.dr. B. Kremer; prof.dr.ir. T. Francart, KU Leuven; Co-supervisor: dr.ir. J. Brokx.

Koenraad Meuwissen, **Burst Spinal Cord Stimulation in a Rat Model of Chronic Neuropathic Pain: Spinal and Supraspinal Mechanisms**. Supervisors: prof. dr. E.A.J. Joosten; prof. dr. M. van Kleef.

Lisa Schmiedek, **Episodic memory in ageing and AD: a possible target for electrical stimulation ?** Supervisors: prof. dr. F.R.J. Verhey; prof. dr. A.T. Sack; co-supervisor: dr. H.I.L. Jacobs

Paolo Maino, **Implantable Intrathecal Drug Delivery in Treatment of Chronic Intractable Pain and Spasticity: Improvement of Safety and the Use of Imaging Techniques.** Supervisors: prof. dr. E.A. Joosten; prof. dr. M. van Kleef.

José Geurts, **Chronic Pain; Impact of Chronic Pain on a Societal, Personal, and Treatment Level.** Supervisors: prof. dr. C.D. Dirksen; prof.dr. M. van Kleef; co-supervisor: dr. P.C. Willems.

Brigitte Brouwer, **Painful Small Fiber Neuropathy; Symptoms, assessments and interventions.** Supervisor: prof. dr. C.F. Faber; co-supervisors: dr. I.S.J. Merkies, Willemstad, Curaçao; dr. J.G.J. Hoeijmakers.

Ruth Gussenhoven, **Antenatal inflammatory insults and preterm brain injury: Pathophysiology and therapeutic strategies.** Supervisors: prof. dr. B.W. Kramer; prof. dr. L.J.I. Zimmermann; Dr. T.G.A.M. Wolffs.

Adriana (Janine) Collet, **Specific Care on the Interface of Mental health and Nursing home "SpeCIMeN".** Supervisors: prof. dr. M.E. de Vugt; prof. dr. J.M.G.A. Schols; Prof. dr. F.R.J. Verhey.

Fares Nigim, **Glioblastoma and Meningioma Biology, Targeted Therapy and Oncolytic Virus Therapy.** Supervisors: prof. dr. Y. Temel; prof. dr. S.D. Rabkin, Harvard; co- supervisors: dr. H. Wakimoto, Harvard; dr. L. Ackermans.

Leonie Banning, **Neuropsychiatric symptoms in Alzheimer's disease; Associations with biomarkers.** Supervisor: prof. dr. F.R.J. Verhey; co-supervisors: dr. P. Aalten; Dr. I.H.G.B. Ramakers.

Johan Haumann, **Prevalence and pharmacological treatment of pain in patients with cancer; The role of opioids with and without NMDA receptor affinity**. Supervisor: prof.dr. E.A. Joosten; co-supervisors: Prof.dr. M.H.J. van den Beuken-van Everdingen; dr. S.M.J. Van Kuijk.

Joost Riphagen, **Vascular matters in aging and dementia**. Supervisor: prof.dr. F.R.J. Verhey; co-supervisor: Dr. H.I.L. Jacobs.

Nikos Priovoulos, **Structural and functional imaging of the locus coeruleus at 7T: from methodological to clinical application**. Supervisor: prof.dr. F.R.J. Verhey; co-supervisors: Dr. H.I.L. Jacobs; dr. B.A. Poser.

Simone Verhagen, **The power of individual landscapes; A clinical exploration of personal experience sampling and new horizons**. Supervisors: prof.dr. P.A.E.G. Delespaul; prof.dr. J.J. van Os, UM/UU; co-supervisor: dr. C.J.P. Simons.

Nagy Youssef, **Epigenetics, resilience and brain stimulation: advances in the mechanistic and therapeutic utility in patients with affective (PTSD and mood) disorders**. Supervisor: Prof.dr. B.P.F. Rutten; co-supervisor: Prof. dr. P. Sienaert, KU Leuven.

Abhishek Appaji, **Retinal vascular features as a biomarker for psychiatric disorders.** Supervisor: Prof. Dr. C.A.B. Webers; co-supervisor: Dr. T.T.J.M. Berendschot, Dr. Naren P. Rao.

Koos Hovinga, **Angiogenesis Inhibition in Glioblastoma.** Supervisor: prof. dr. Y. Temel; co-supervisor: Prof. V. Tabar, New York, USA.

Gerhard Drenthen, **Myelin and networks, Magnetic Resonance Imaging in Epilepsy.** Supervisors: prof. dr.ir. W.H. Backes; Prof.dr. A.P. Aldenkamp; co-supervisor: dr. J.F.A. Jansen.

Anna Gorlova, **Understanding the Molecular Mechanisms of Aggression in BALB/C and TPH2-Deficient Mice.** Supervisor: prof.dr. K. Lesch, Universitätsklinikum Würzburg, co- supervisors: dr. T. Strekalova; prof.dr. L. Bettendorff, University of Liège.

Ekaterina Veniaminova, **The impact of the 'Western Diet' on Emotional, Social and Cognitive Behaviours as revealed by a study on conventional and serotonin Transporter-Deficient Mice**. Supervisor: prof.dr. K. Lesch, Universitätsklinikum Würzburg, co-supervisors: dr. T. Strekalova; prof. D.C. Anthony, Oxford.

Dmitrii Pavlov, **The contribution of CNS inflammation and Glycogen Synthase Kinase-3 (GSK-3)-cascades on adverse memory learning on mouse models of emotional stress**. Supervisor: prof. dr. K. Lesch, Universitätsklinikum Würzburg, co-supervisors: dr. T. Strekalova; prof.dr. L. Bettendorff, University of Liège.

Eric Fonseca Wald, **Absence Epilepsy and Panayiotopoulos Synrome: Neurocognition and Brain Development**. Supervisor: prof.dr. R.J. Vermeulen; co-supervisors: Dr. S. Klinkenberg; dr. M.J.A. Debeij-van Hall; Dr. J.G.M. Hendriksen, Epilepsiecentrum Kempenhaeghe.

Kimberley S. Noij, **Cervical vestibular evoked myogenic potentials; Toward optimizing clinical use**. Supervisors: prof.dr. H. Kingma; prof. S.D. Rauch, MD, Massachusetts Eye and Ear, Harvard; co-supervisor: Dr. R. van de Berg.

Mark J. van Tilburg, **Advancement in cVEMP's**. Supervisors: prof.dr. H. Kingma; prof.dr. S. Rauch, Harvard; co-supervisors: dr. R. van de Berg; dr. B. Herrmann, Boston.

Nalini Atcharayam, **Duchenne Muscular Dystrophy: The NIMHANS Experience**. Supervisors: prof.dr. T. Delhaas; prof.dr. B.W. Kramer.

Murat L Atagün, **Cognitive neurophsysiology and neurochemistry in bipolar disorder**. Supervisor: Prof. Dr. Therese van Amelsvoort; co-supervisors: Dr. Sinan Guloksuz; Dr. Marian Drukker.

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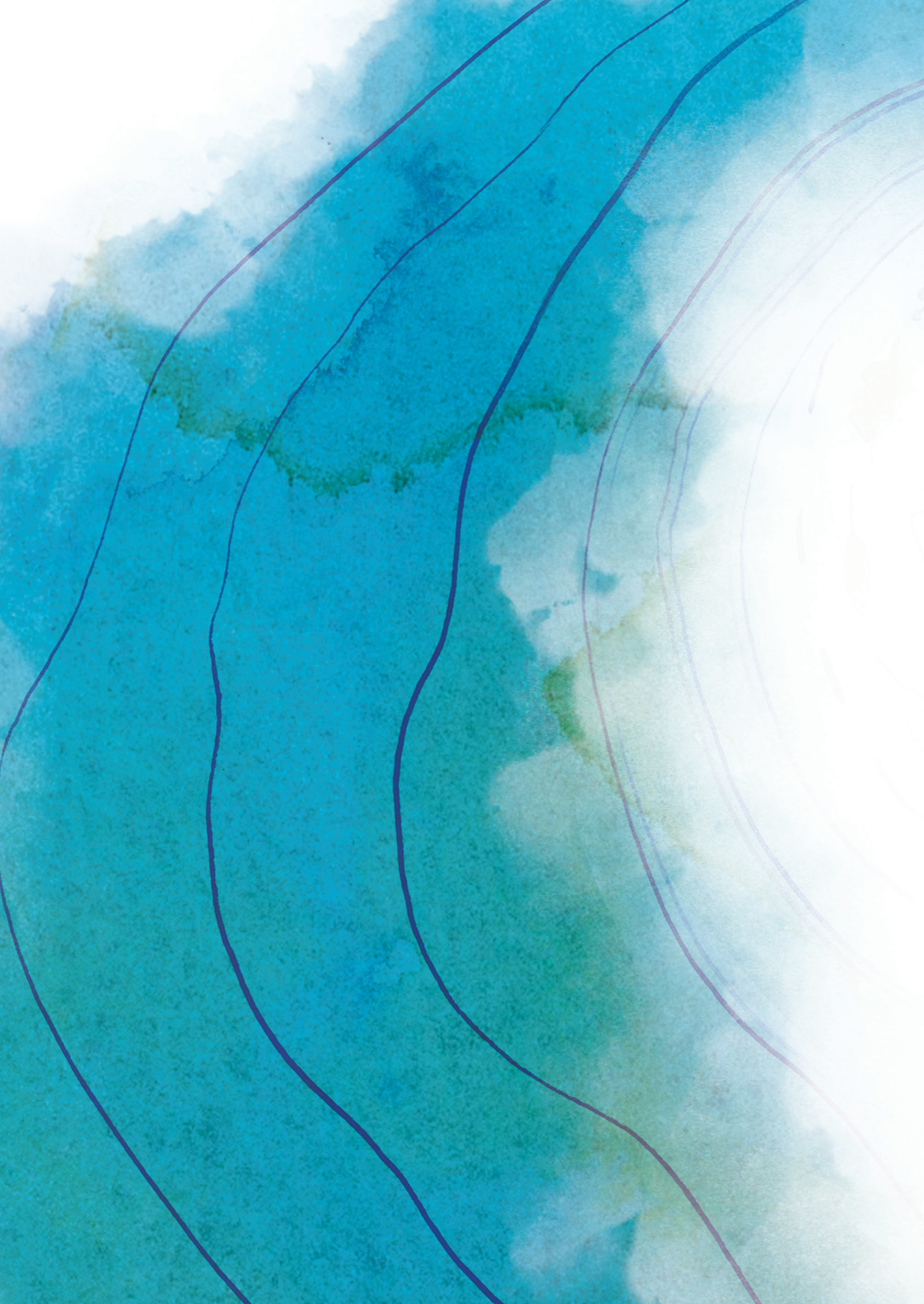

Addendum

About the author

About the author

Sara Laureen Bartels was born on September 17th, 1992, in Langenhagen, Germany. After graduating from secondary school (Gymnasium) at Ludwig-Meyn Schule in Uetersen (2011), Sara moved to Hamburg to study Psychology at the MSH Medical School Hamburg. During her studies, she received two MSH scholarships and completed a clinical internship at the University Hospital in Cologne. There, Sara was involved in the diagnostic process for adults on the autism spectrum at a specialized department and conducted neuropsychological assessments at a memory clinic. She completed her Bachelor's in 2014. Subsequently, she gained practical experiences at a rehabilitation centre and a care home for people with chronic mental illness in Aachen. In 2015, Sara enrolled in the one-year Master's program Neuropsychology at Maastricht University. As part of it, she spent six months at the Oxford University Hospital researching memory and attention in posterior cortical atrophy, before graduating cum laude in 2016.

Immediately after, Sara got selected to join the Marie Skłodowska Curie Actions – Innovative Training Network 'INDUCT' as an early stage researcher and PhD student based at Maastricht University and the Alzheimer Centre Limburg. Her PhD project focused on using the experience sampling method and technology to understanding and support various aspects of everyday life in different aging populations. During her trajectory, she was also involved in several other research projects, academic event planning, and presented her work nationally and internationally. Sara spend several months each at a Dutch company, called EuMedianet, as well as at the Department of Occupational Therapy at Karolinska Institutet, Sweden, to gain valuable insights into different sectors and disciplines. Currently, Sara is affiliated to Karolinska Institutet and based in Stockholm, while working as a postdoctoral researcher remotely for the same Department of Maastricht University.