



Illuminating daily struggles related to sleep disorders

VAIDA VERHOEF, MSC.

SUPERVISOR TEAM: PR.DR.IR. YVONNE DE KORT, PR.DR. SEBASTIAAN OVEREEM, DR.IR. KARIN SMOLDERS



TO START

Excessive daytime sleepiness (EDS) is a frequent concern among the clinical and the non-clinical population^{1,2}. Despite its high prevalence, daytime sleepiness remains difficult for people to describe and thus to recognize, diagnosed and treat^{3,4}.

Generally defined as a propensity to sleep, sleepiness is often called tiredness, misjudged as fatigue, or described as a lack of alertness, attention or vigilance^{3,5,6}. The overlapping constructs around sleepiness mirror the multitude of assessments methods and contribute to the complexity of sleepiness detection³.

Further research is needed in order to improve the detection and monitoring of sleepiness and other sleep related daytime impairments.



A PATIENT CENTERED PERSPECTIVE

A **qualitative study** was performed to gain more insight into what patients suffering from sleep disorders are experiencing and how they describe it. Among **20 patients suffering from narcolepsy or sleep apnoea**, we conducted **semi-directed interviews** centred around the daytime consequences of their diagnosis. The data collected are currently under thematic analysis.

First insights:

- Patients found it important to discuss and share their daytime struggles.
- Different definitions were used to describe sleepiness, fatigue, tiredness and other complaints.
- The terms, metaphors and definitions used by patients don't always correspond to validated subjective measures used by clinicians and researchers.

"Walking through syrup"

"Fog in my head"

"A empty savings account of energy"

"A hollowness"

"A white light in my head"

"Heavy legs"

A FIELD MEASURE OF SLEEPINESS

To investigate the validity, sensitivity, and specificity of new and existing metrics of sleepiness for field assessments, we designed a **quantitative study combining field and lab measures**. We will apply a sleep restriction paradigm among **20 healthy participants**. This will enable us to monitor field-levels of sleepiness in response to the cumulative effect of continuous partial sleep restriction, and compare them to commonly-used and validated lab measures.

The field assessments of sleepiness include:

- Continuous keystroke monitoring
- Self-reports (KSS, SSS, VAS) using the experience sampling method (10 short questionnaires per day)
- Continuous skin temperature recording and Actiwatch monitoring
- Daily questionnaires (ESS, PROMIS) and performance task (PVT)

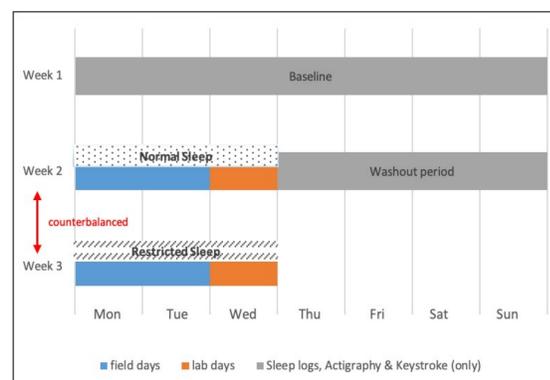


Figure1. Overview of the experiment protocol

A FUTURE IN DAYLIGHT

Insights into the patients' experiences and into field measures of sleepiness will enable us to pursue the main aim of this project:

Investigating how daytime light exposure might benefit patients suffering from sleep disorders.

Future studies will evaluate how the field measures respond to patient's experiences and how they might be affected by daylight and manipulated light exposure patterns.

This endeavour is part of the **LIGHTCAP⁷** consortium, a European project that focuses on the study of both image and non-image forming pathways of light. In particular, this project is part of the second work package, that investigates the effects of light on human's cognition, attention and perception, in both laboratory and field studies.

⁷LIGHTCAP

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¹Thorpy & Billard, 2011; ²Jausse et al., 2017; ³Shahid et al. 2010; ⁴Slater & Steier, 2012; ⁵Shen et al., 2006; ⁶Yun et al., 2015