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# Research in Developmental Disabilities



## Objective assessment of sleep and sleep problems in older adults with intellectual disabilities



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### ABSTRACT

Little is known about sleep in older adults with intellectual disability (ID). Aim of this study was to investigate sleep and its associated factors, and to estimate the prevalence of sleep problems in this population. This study was part of the healthy aging and intellectual disabilities study. Sleep was assessed using the Actiwatch, a watch-like device that measures sleep and wakefulness based on movement activity. Participants ( $n = 551$ ) wore the Actiwatch at least seven days and nights continuously. Variables of interest were time in bed (TIB), sleep onset latency, total sleep time, wake after sleep onset, sleep efficiency and get-up time latency. Multivariate analyses were used to investigate factors associated with these sleep parameters. Provisional definitions were drafted to estimate the prevalence of sleep problems. Mean TIB was 630 min. Longer TIB was independently associated with higher age, more severe level of ID, living at a central facility, wheelchair dependence, female gender and depressive symptoms (adjusted  $R^2 = .358$ ,  $F$ -change = 8.302,  $p < .001$ ). The prevalence of sleep problems was 23.9% settling problem, 63.1% night waking problem, 20.9% short sleep time, 9.3% early waking problem. 72% of the participants had at least one problem, 12.3% had three or more sleep problems. Older adults with ID lie in bed very long, and the prevalence of sleep problems is high. Further research should focus on causality of the relationships found in this study, and effects of sleep problems on health and well-being in this population.

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### 1. Introduction

Sleep deprivation has a negative impact on general well-being (Balkin, Rupp, Picchioni, & Wesensten, 2008), and short sleep duration and insomnia symptoms are associated with lower health related quality of life (Magee, Caputi, & Iverson, 2011; Schubert et al., 2002). In people with intellectual disabilities (ID), sleep problems are common (Espie, 2000), with estimated prevalences of sleep problems in adults of 8.5–34% (Wouw, Evenhuis, & Ehteld, 2012). Because people with ID are often not capable of communicating their sleep problems, previous research in this population was mainly based on caregiver interviews and questionnaire surveys (van de Wouw, Evenhuis, & Ehteld, 2012). Such information is possibly influenced by recall and observation bias, or caregivers may selectively report problems that are disturbing for the environment (Brylewski & Wiggs, 1998). This might lead to an underestimation of sleep problems. Further, previous research has mainly focused on children and adults. Only few studies that focused on dementia in older adults with ID, involved some information about sleep disturbances (Cooper, 1997; Cooper & Prasher, 1998; Urv, Zigman, & Silverman, 2008). Otherwise very little is known about sleep and sleep problems in older adults in this population.

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In older adults in the general population, sleep complaints are highly prevalent (Ancoli-Israel, 2009; Cochen et al., 2009; Cooke & Ancoli-Israel, 2006; Neikrug & Ancoli-Israel, 2010; National Sleep Foundation, 2003; Roepke & Ancoli-Israel, 2010). The circadian sleep–wake rhythm changes with aging because of degeneration of the suprachiasmatic nucleus, which is the circadian pacemaker in the brain (Swaab, Fliers, & Partiman, 1985; van Someren, 2000), resulting in disrupted sleep–wake patterns (Roepke & Ancoli-Israel, 2010; van Someren, 2000). Apart from age-related changes, sleep disturbances in older adults may be secondary to medical and psychiatric co-morbid conditions (Foley, Ancoli-Israel, Britz, & Walsh, 2004; Grandner et al., 2012; Vaz Fragoso & Gill, 2007), like chronic pain, cardiovascular disease, pulmonary disease and gastrointestinal disorders, and medication use (Ancoli-Israel, Ayalon, & Salzman, 2008). Environmental factors influence sleep quality as well. For example, in elderly people living in a nursing home, disrupted sleep and poor sleep quality frequently occur due to nighttime noise and light exposure (Cooke & Ancoli-Israel, 2006).

In adults with ID, reported factors that are associated with sleep problems are challenging behavior (for example aggression and self-injurious behavior), respiratory disease, visual impairment, psychiatric conditions, and the use of psychotropic, antiepileptic and/or antidepressant medication (van de Wouw et al., 2012). Also, sleep–wake schedules for people with ID are often adapted to the work schedules of professional caregivers (Hylkema & Vlaskamp, 2009), which can contribute to sleep difficulties. As sleep is regulated in the brain, the neurological pathology in people with ID may also contribute to sleep problems in this population (Doran, Harvey, & Horner, 2006).

Life expectancy has increased for people with ID, and aging in those with a mild ID is similar to that in the general population (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). However, health problems like epilepsy, musculoskeletal disability, visual and hearing problems occur more frequently in people with ID compared to the general population (van Schrojenstein Lantman de Valk, Metsemakers, Haveman, & Crebolder, 2000). Sleep architecture changes as a result of aging, and combined with more co-morbidity, preexistent brain damage and dependency on caregivers, older adults with ID might be extra vulnerable to sleep problems. Because caregivers are not always close to their clients at night, objective assessment of sleep patterns is desirable. Polysomnography is the gold standard to study sleep patterns, but this method is expensive and can be stressful for people with ID. A more suitable method to investigate sleep in this population is actigraphy, which is a method that is increasingly used in sleep research (Morgenthaler et al., 2007). An actigraph is a device designed to measure sleep parameters and sleep–wake patterns based on motor activity (Sadeh & Acebo, 2002). Usually, an actigraph is a watch-like device that can be worn on the wrist. Actigraphy is non-invasive, does not hamper normal activities and enables continuous measurement in the home environment during a longer time (Hyde et al., 2007; Lichstein et al., 2006; Tonetti, Pasquini, Fabbri, Belluzzi, & Natale, 2008).

Because little is known about the distribution of objective sleep parameters and factors specifically influencing these sleep parameters in older adults with ID, the aim of this study was to investigate sleep and its associated factors in this population, using actigraphy. Research questions were (1) How is the distribution and inter-correlation of objective sleep parameters in older adults with ID? (2) Which factors (demographic, co-morbid conditions and medication use) are independently associated with these sleep parameters? and (3) What is the estimated prevalence of sleep problems in older adults with ID?

## 2. Methods

### 2.1. Study design and participants

This study was part a cross-sectional descriptive study, titled 'healthy aging and intellectual disabilities' (HA-ID). HA-ID is addressing health in 1050 older adults (aged 50 years and older) with intellectual disabilities (ID) in The Netherlands. Details about design and recruitment of the sample, as well as diagnostic methods, have been presented elsewhere (Hilgenkamp et al., 2011). Informed consent was acquired from all participants (if able to give informed consent themselves) or from their legal representatives. Participants who refused to wear the measurement instrument themselves, or were known by their professional caregivers to easily lose or break things were excluded from the study.

The study was approved by the Medical Ethical Committee of the Erasmus Medical Center (MEC 2008-234) and by the ethical committees of the participating care-providers. The study adheres to the Declaration of Helsinki for research involving human subjects.

### 2.2. Materials

#### 2.2.1. Variables of interest

Variables of interest were factors that might influence sleep in this population that had been measured in the HA-ID study, and had a prevalence of  $\geq 5\%$  (for sufficient statistical power). They concerned demographic information (gender, age, level of ID and residential status), co-morbid conditions (autism spectrum disorder, depression, anxiety, psychosis, severe behavioral disorders, dementia, epilepsy, visual impairment, hearing impairment, respiratory disorder, gastro-esophageal reflux disease, chronic constipation, scoliosis, spasticity, hypothyroidism and cardiovascular disease), use of medication with sedative effects (anti-epileptics, benzodiazepines, antidepressants, antipsychotics and melatonin), body mass index (BMI), mobility and daycare occupation.

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