Significance and phenomenology of non-rapid eye movement (NREM) parasomnias. Data from a representative population survey, YouTube video collection, and clinical experiences

PhD thesis booklet

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1. Introduction

NREM parasomnias, also termed disorders of arousal (DOA), constitute a curious and mysterious group of conditions manifesting undesired behaviors during non-rapid eye movement sleep. These conditions challenge our notion about sleep; the episodes present with parallel sleep-like and wake-like phenomena, partial awareness, and partial sleep. While there is ongoing research and an abundance of studies trying to understand these conditions, much data on the prevalence, facilitating factors, and consequences (often injurious or dangerous) of DOA, as well as on the impact of genetic, psychological, and environmental factors, remains vague and contradictory.

The different kinds of study populations (sleep laboratory and sleep clinic patients, psychiatry in- and outpatients), heterogeneous data-collection methods (retrospective analyses, questionnaires, telephone interviews, targeted web-based surveys mostly involving persons affected in some way, etc.) may have caused inconsistencies in the results. Population surveys rely purely on the affected persons' self-reports, mostly reporting little or no recollection of their episodes. In

those studies, usually no historical data or medical diagnoses are provided. In these surveys, people may be unwilling to disclose sensitive or confidential data to the generally non-medical questionnaire. Studies based on sleep clinics' and especially sleep laboratory patients represent selected, severe, and complex populations; many of those persons seek medical help for the high frequency or injurious consequences of the episodes; they represent, by no means, the population's average. I aimed to overcome those limitations as much as possible by applying each method, criticizing them, and finally, trying to combine the results to draw conclusions.

2 Objectives

The aim was to collect data on the epidemiology, phenotypes, and contributory factors of adult NREM parasomnias in three approaches: a cross-sectional representative population survey, YouTube videos, and a retrospective review of the database of Semmelweis University's Sleep clinic to investigate the following questions:

1. What is the prevalence of NREM parasomnias in Hungary?
2. What is the proportion of different subtypes?
3. What is the rate of potentially dangerous activities during NREM parasomnia episodes?
4. How often is there a family accumulation of NREM parasomnias?
5. Do ACEs influence the occurrence of NREM parasomnias?

3 Methods of the three studies

A) Data representing the Hungarian population in 2023

A community-based representative survey was conducted between February 28 and March 8, 2023, targeting adults aged 18 and above in Hungary. A paid professional pollster company, Závecz Research, selected the participants using the "random walk method", using a computer-assisted method via laptops or tablets. The survey encompassed independent sociodemographic variables such as age

group (19-30, 31-49, or ≥50), biological sex, residence (urban or rural; residence of county), and education level (primary, secondary, or graduated), stratified by regional demographics from the last census. After collecting sociodemographic data, participants were queried about their sleep-related activities, family history of parasomnias, whether they had experienced ACE, and their potential engagement in risky behaviors during their episodes by the following questions:

1. Have you ever (or have you ever been told that you) got out of bed and sleepwalked or performed other sleep-related activities? (Yes/No/do not know)
2. What activities did you perform during sleep? (open text)
3. Do you have any family members who have experienced sleep-related activities/parasomnias? (Yes/No/do not know)
4. Have you performed any dangerous or injurious activity during sleep? (e.g., climbing or jumping out through the window, leaving the house, falling from the bed, driving in sleep, etc.) (Yes/No/do not know)

5. Have you experienced any physical or mental adverse/traumatic experiences in your childhood?
6. Would you like to describe them? (open text)

B) Data collection from YouTube videos on sleep-related behaviors likely to represent NREM parasomnias

The terms “sleepwalking,” “somnambulism,” “sleep eating,” “sleep sex,” “sleep terror,” and “sleep talking” were applied to a YouTube search (https://www.youtube.com) between January and July 2022. Two scorers estimated the biological sex and age of those persons in the videos. We set up two sexes (M/F) and three estimated age groups (child or adolescent ≤17 years; adult between 18 and 50 years; and older adults over 50 years).

Binary logistic regression was used to assess the relationship between sleep-related behaviors and other variables, scaling and applying it to activity types. Some records showed more than one type of activity; each one was classified as either present or absent based on our self-made list of activities, as follows:

Statistical analysis for the methodology A and B

Binary logistic regression assessed the association between parasomnias and variables, with chi-square tests and odds ratios (ORs) reported with 95% confidence intervals (CIs). We coded missing data and "do not know" responses ‘conservatively’ as "No". More significant disparities from an OR of 1 indicated stronger associations between variables. The STATA statistical package computed ORs and 95% CIs for each activity type. (StataCorp. 2019. Stata Statistical Software: College Station, TX: StataCorp LLC).

C) *Experiences on adult parasomnias seen in the Sleep Clinic of the Institute of Behavioral Sciences, Semmelweis University, between 2018 and 2023*

I performed a retrospective analysis of patient records. Using Microsoft Excel for computing descriptive statistics, as types of dangerous activities among NREM parasomnia-like activities, and the age slope on prevalence of DOA.

4 Results of the three studies

A) Data representing the Hungarian population in 2023

Of the 1,000 participants, 70% were urban dwellers, and 30% lived in rural areas. The mean age was 48 years (SD: 16.75, range 18–90 years), 53% were females, and 50% had primary education. The open-text question targeted the types of activities during sleep. Out of the 1000 participants, twenty-seven reported sleep-related activities that we suspected to be consistent with NREM parasomnia episodes. Six persons (18%) of those 27 reported having performed dangerous behaviors during the episodes. Our binary logistic regression results showed a significant age difference (OR 0.3, 1.10-0.80, P:0.03), in which the probability of sleep-related activities - likely DOA - was significantly lower in older adults than in younger adults. Twenty-six percent of those reporting sleep-related activities reported a family occurrence of them. The probability was 7.1-fold in those having one or more family members experiencing DOA compared to non-familial cases. Among the DOA cases, 33% reported adverse childhood experiences. A significant association of adverse childhood

experiences was found, more than six times higher (OR 6.2, 2.53–14.96, P <0.001) in people with reported DOA compared to those without.

B) *Data collection from YouTube videos on sleep-related behaviors likely to represent NREM parasomnias*

After excluding 551 videos (17 apparent RBD- and epilepsy cases, 534 poor quality-, likely faked, entertainment and advertisement records), 207 have remained, likely consistent with NREM parasomnias (showing 102 women, 68 children, 116 adults, and 23 older adults). The binary logistic regression results have shown that individuals estimated to be over 50 years old exhibited significantly lower odds of sleepwalking than adults and children. Additionally, adults had significantly higher odds of dangerous activities than those older than 50 years. Only two videos of sleep terror were found, and three videos related to sexual activity were identified; these videos were parts of educational materials uploaded to YouTube. Also, SRED had no association with age or biological sex groups; however, 75.8%

of dangerous activity types during NREM parasomnia-like activities were found to be SRED.

C) *Experiences on adult parasomnias seen in the Sleep Clinic of the Institute of Behavioral Sciences, Semmelweis University, between 2018 and 2023*

Over 5 years, between 2018 and 2023, 45 parasomnia cases were seen, and 36 of them were likely consistent with NREM parasomnias, based on clinical data and, in several but not all cases, video-polysomnography. Sleepwalking, sexsomnia, and sleep eating were noted. The small, non-representative group does not allow drawing conclusions that would be valid for the population; however, we found the occurrence of parasomnia types in this highly selected patient group interesting. The data supported the high risk of injuries; 36.1% of the patients seen experienced dangerous activities and injuries; four persons experienced severe injuries. We found 7 patients reporting a family accumulation of DOA (19.5%). Three persons reported sleep-related eating, and two persons reported sexsomnia.

D) *Synopsis of results*

The prevalence of NREM parasomnias, types, dangerous activities, and ACEs by the three data collection methods is shown in **Table 1**. We found an 'age slope' from children through adults and older adults, with a decreasing prevalence of DOA, especially sleepwalking, by each method.

Table 1. Comparison of results by the three methodologies (N, percentages of DOA, and dangerous activities)

	Population survey	**YouTube-videos***	**Clinical research***
DOA persons (N)	27	207	36
Sleepwalking	81.5 %	31.8 %	86.1 %
Sleep eating	3.7%	12.1%	8.3%
Sleep talking	14.8%	60.4%	-
Sleep terror	-	0.9%	-
Sexsomnia	-	1.4%	5.5%
Dangerous activities	18.5%	15.9%	8.3%

5 Conclusions

Our study reveals that adult NREM parasomnias, as relatively frequent conditions, may be linked to lifestyle, medical, psychological, and substance (alcohol and drugs) – related issues. These conditions carry significant health hazards and may compromise the quality of life of those affected.

In our study conducted from a representative population survey in Hungary, the prevalence of adult sleepwalking was slightly different from that of other regions. Our study seems to be one of the few representative surveys on the prevalence of SRED (affecting 0.1% of the population). As a usually forgotten or overlooked condition not included in the group of eating disorders, it needs awareness and attention. Clinicians need to know provoking drugs, especially psychoactive ones.

The remarkably high occurrence of sexsomnia in our retrospective clinical study highlights that this kind of DOA really exists, and it may have a higher prevalence than expected. Naturally, identifying this sensitive phenomenon requires confidential medical exploration. It needs to be considered in certain forensic cases of sexual crime.

The rate of dangerous behaviors was higher than in most studies: the risk of injury was significant for each methodology. By acknowledging this and implementing appropriate precautions, affected individuals could be protected, and risks associated with sleep-related activities mitigated; our results underscore the importance of safety measures and risk management. The 14.8% proportion of DOA-like individuals reporting adverse childhood experiences supports the possibility of traumatic experiences' long-term neurobiological impact on the genesis of NREM parasomnias. The family accumulation affecting just about one-quarter of adult DOA persons suggests that inheritance has a subsidiary impact on adult DOA, leading to DOA combined with lifestyle issues and historic adverse events. Whether ACE-related and familial cases manifest the same phenotypes needs further study.

We found an age-slope of sleepwalking; it is most prevalent in children and has a decreasing rate in adults and further in the elderly. We still need to make considerable progress in uncovering the underlying causes of NREM parasomnias, including this age association.

New findings were the followings:

- To our knowledge, this is the first representative study on adult parasomnias in Hungary, finding prevalence rates of sleepwalking similar to most international data.
- We found a considerably lower prevalence of SRED than the scarce international data did. We found its prevalence at 0.1% of the Hungarian population, similar to the prevalence of anorexia nervosa. Therefore, SRED needs awareness and attention, as well as a potential side-effect of several psychoactive medications, especially zolpidem and quetiapine.
- The high occurrence (5.5%) of sexsomnia reported in our sleep clinic cohort is similar to that of other sleep clinics presented in the literature and suggests a higher prevalence than expected. It needs awareness and to be considered as a medico-legal issue in some sexual crimes as an NREM parasomnia-related automatism.
- We found a high occurrence of dangerous behaviors during sleep-related episodes in each study, highlighting that adult parasomnias carry important risks of injury.
- Having DOA was six times more probable (OR 6.2; $P < 0.001$) in those people reporting ACEs, compared to those not reporting

them, highlighting the potential harm of childhood adversities in the development of adult parasomnias.

- The high occurrence of reported childhood adversities in the population survey requires attention in childcare.

6 Bibliography of the candidate's publications

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NREM parasomnia-related behaviors and adverse childhood experiences

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Congress Abstract Speaker

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Parasomnias in Hungary. A high association with adverse childhood experiences

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