

Sleep Disturbances in ME/CFS

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Agenda

1. Prevalence of sleep disorders in the general population
2. Sleep disturbances as a CFS symptom
3. Sleep medical examination
4. Preliminary results of the CFS-Care-study
5. Conclusions

1. Prevalence of sleep disorders in the general population

- **Chronic insomnia** (*according Ohayon MM 2002 & 2009 and www.dak.de/presse*)
 - More frequent in women and increasing with age
 - Every third German inhabitant describes sleep disturbances but only every 5th suffers from sleep disturbances at least at 3 nights per week and every 16th inhabitant meets the strict Diagnostic and Statistical Manual (DSM)-IV-criteria.
 - Different classification systems: international classification of sleep disorders ICSD (AASM), ICD (WHO), DSM (APA)
 - DAK Gesundheitsreport 2017: Extrapolated to the population 34 million inhabitants suffer in Germany from sleep disturbances and from chronic insomnia every tenth employee.
- **Obstructive sleep apnea** (*Fietze et al. 2019*)
 - More frequent in men and increasing with age
 - SHIP-Trend-Study (Study of Health in Pomerania): 21% suffer from moderate/severe OSA (apnea-hypopnoe-index (AHI) $\geq 15/h$)
- **Restless Legs Syndrome (RLS)** (*Oertel et al. 2000, Szentkirályi et al. 2019, Broström et al. 2023*)
 - More frequent in women and increasing with age
 - 9.5% of the German general population
- **Delayed sleep phase syndrome** (*Saxvig et al. 2012, Sivertsen et al. 2013, Gradisar et al. 2013*)
 - 1 - 16% in adolescents and young adults
- **Narcolepsy, hypersomnia, parasomnias, further movement disorders in sleep, other sleep disorders**
 - Each < 1% of the general population

2. Sleep disturbances as a CFS symptom

- **All classifications** describe sleep disturbances as a possible CFS symptom.
- **Some classifications** describe sleep disturbances as an obligate CFS symptom :
 1. National Institute for Health and Care Excellence, NICE (2021):
 2. Institute of Medicine, IoM (2015):
 3. Canadian Consensus Criteria, CCC (2003): „ Sleep Dysfunction: There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms“.
 - "It is also essential to exclude treatable sleep disorders such as... sleep apnea and restless legs syndrome“.
 - “If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.”

References:

1. ME (or encephalopathy)/CFS: diagnosis and management. London: National Institute for Health and Care Excellence (NICE); 2021.
2. Institute of Medicine (U.S.), editor. Beyond ME/CFS: redefining an illness. Washington, D.C: The National Academies Press; 2015. 282 S.
3. Carruthers ME CFS: Clinical Working Case Definition, Diagnostic and Treatment Protocols. J Chronic Fatigue Syndr. 2003;11(1):7–115.

3. Organization of the sleep medical diagnostics in general and in CFS patients

Obligate	mostly	optional
1	2	3
Medical history by a sleep medicine expert & questionnaires	Home sleep testing	Sleep diaries actigraphy Sleep lab: polysomnography (PSG) multiple sleep latency test (MSLT)

Caution: normal home sleep testing does not rule out sleep apnea !

CFS-Care-study (preliminary n = 64) : how many patients suffer from a sleep disorder?

According to International Classification of Sleep disorders, 3th edition

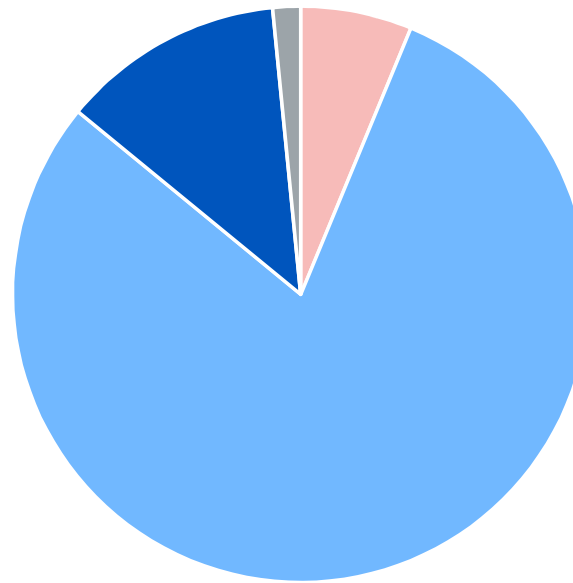
Number of participants without a sleep medical disorder or with one, two, or three sleep medical disorders

■ no sleep disorder n = 4

■ one sleep disorder n = 51

■ two sleep disorders n = 8

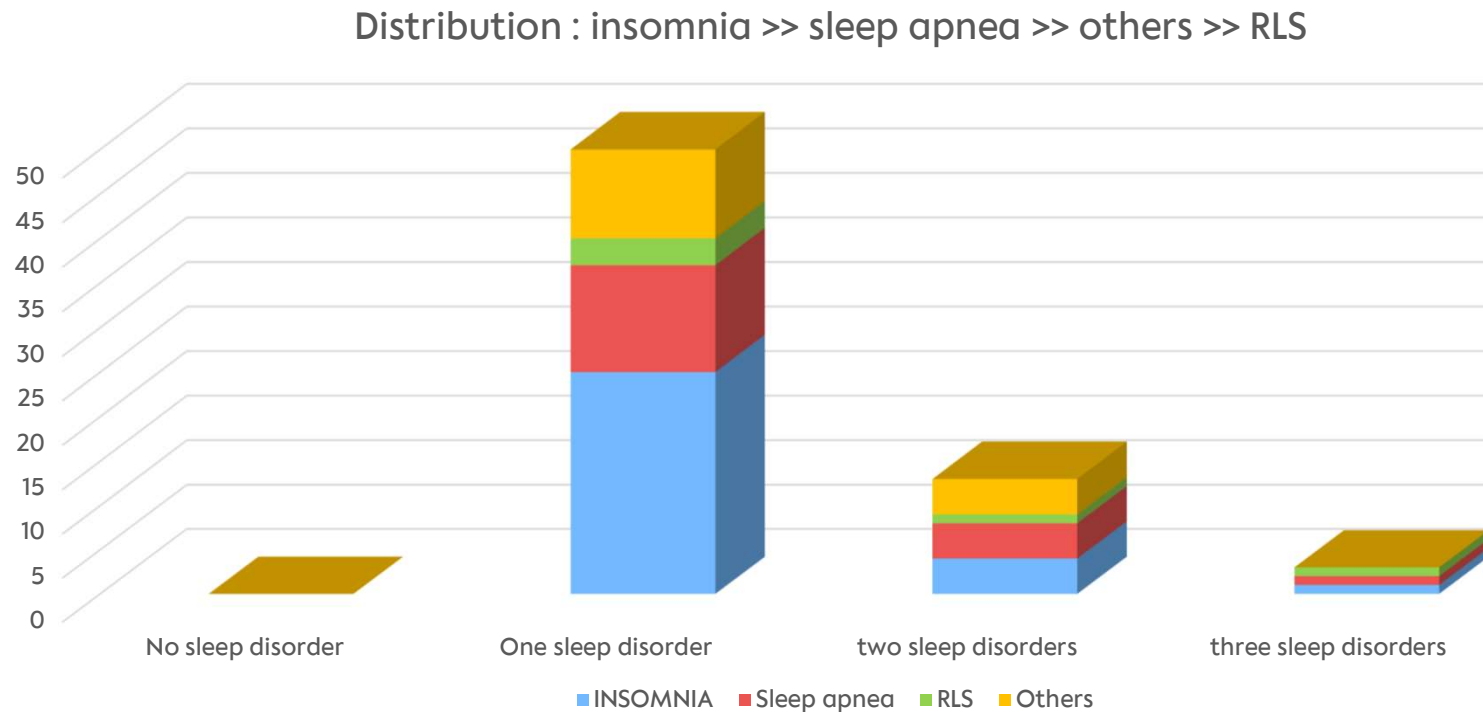
■ three sleep disorders n = 1



Minor sleep disturbances such as nocturia, snoring, or mild sleep disturbances were not considered sleep medical conditions.

Distribution of diseases in patients with one, two or three diagnoses

According International Classification of Sleep disorders, 3th edition



Insomnia n = 26

Sleep apnea n = 17

RLS n = 5

Others n = 14

Sleep walking n = 1

Hypersomnia (suspicion) n = 5

Delayed sleep phase syndrome n = 5

Nightmares almost every night n = 2

Severe bruxism n = 1

Conclusions

1. Sleep disorders seem to be common in ME/CFS.
2. Do not overlook delayed sleep phase syndrome and use sleep diaries !
3. Do not overlook RLS and ask for the essential RLS criteria !
4. Do not overlook OSA and make sleep home testings !
5. Treat insomnia according to the guidelines !
6. Do not hesitate to refer to the sleep expert !
7. We hope to be able to tell you at the next congress whether treatment of underlying sleep disorders improves fatigue.

Thank you for your attention !

Questions ?