

Disruptive Sleep in Developmental and Epileptic Encephalopathies: Interim Results of a Caregiver Survey

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Background

- Developmental and epileptic encephalopathies (DEEs), characterized by high seizure burden and developmental disability,¹ can cause sleep problems² and behavioral difficulties,³ which can in turn affect quality of life (QoL) of patients, their caregivers, and their siblings⁴
- Caregiver definitions of "normal" and "disruptive" sleep have not been extensively explored

Objective

- To define normal and disruptive sleep patterns in individuals with DEE
- To explore the caregiver-observed association between disruptive sleep and temporary loss of ability to perform activities of daily living (ADLs) and to communicate

Methods

- An anonymous, internet-based, 63-question survey, developed in consultation with the Dravet Syndrome Foundation and Lennox-Gastaut Syndrome Foundation, was distributed to caregivers of individuals with DEEs via DEE-specific communities (March 11 through April 30, 2024)
 - Criteria: primary caregiver to, or helps care for, an individual diagnosed with DEE
- The survey was designed to define, for each individual with DEE, normal and disruptive seizures, sleep, and behavior, and to determine how often those disruptions affect communication and ADLs (Table 1)

Table 1. Descriptions of the Five Key Domains in the Survey

Domain	Description
Seizures	Frequency, clustering, and average length of seizure; duration of seizure freedom; rescue medication/device use
Sleep	Number of >30 min awakenings, amount of total sleep per night; number of awakenings with inability to return to sleep per week
Behavior, disruptive	Any of the following – hitting, biting, kicking, shouting, hair pulling, swearing, harsh language, throwing objects, refusal to cooperate, destruction of property, threatening physical harm, invading an individual's personal space, anger
ADLs	Feeding; toileting; bathing/personal hygiene; dressing
Communication	Basic methods, tools, or devices used to exchange information

ADLs, activities of daily living.

- The current analysis explores data specific to normal and disruptive sleep, including relationships between disruptive sleep and ADLs/communication
- Other variables, such as the use of a nighttime device (eg, seizure monitoring device [SMD]), caregiver wakes due to an SMD alerting even without seizure activity (SMD false alarms), co-sleeping, medication/medical device side effects, daytime/nocturnal seizures, and postictal periods were also examined

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Overview

QUESTIONS

- What is the relationship between disruptive sleep patterns in individuals with developmental and epileptic encephalopathy (DEE) and the temporary loss in their ability to perform activities of daily living and to communicate?
- What is the relationship between co-sleeping or seizure monitoring device use and the caregiver's sleep?

INVESTIGATION

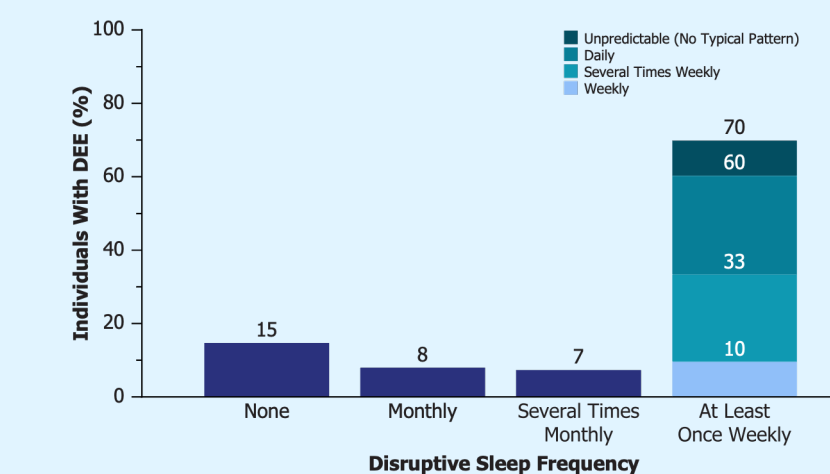
- An internet-based anonymous survey was distributed via patient advocacy websites, social media, and patient community events
- Respondents were primary caregivers to an individual diagnosed with DEE
- Here, normal and disruptive sleep, as defined for each individual with DEE, was examined

Definitions of experiences for individuals with DEE included in the survey:

- Normal:** the typical daily experience during the current phase of the DEE journey
- Disruptive:** a deviation from the normal daily experience
- Always disruptive:** no pattern or distinguishable "typical" experience

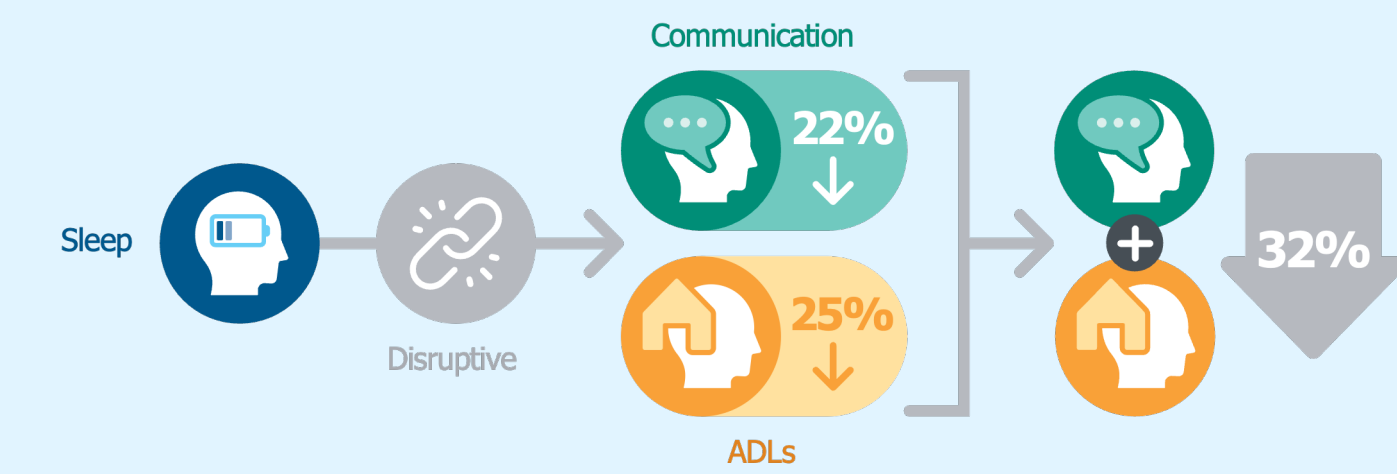
RESULTS

Approximately 70% of Individuals With DEE Experience Disruptive Sleep At Least Once Per Week (N=489)



"At least once weekly" is defined as weekly (9.6%), several times weekly (23.7%), daily (27.0%), and unpredictable (no typical pattern; 9.6%).

Disruptive Sleep Was Associated With the Temporary Loss of Ability to Perform ≥1 ADL or to Communicate in 24.5% and 21.5% of Individuals With DEE, Respectively



Disruptive sleep was associated with temporary loss of either the ability to perform an ADL or to communicate in 32.3% of individuals. ADLs include feeding, dressing, toileting, and bathing/hygiene.

CONCLUSIONS

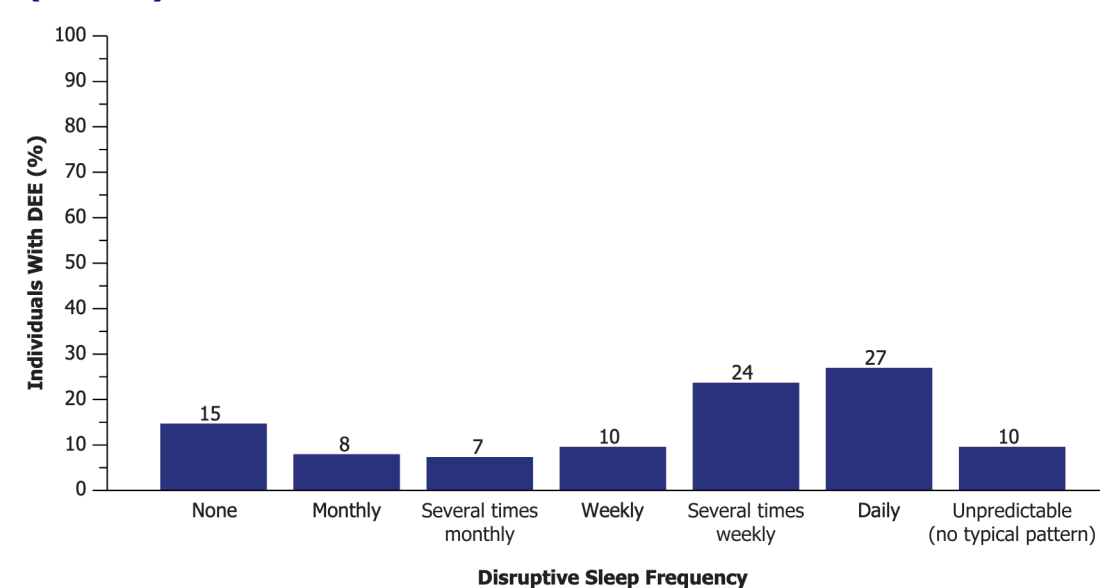
- Sleep disturbances in approximately a quarter of individuals with DEE were associated with temporary loss of an ADL or communication
- Reducing disruptive sleep may improve quality of life in individuals with DEE and their caregivers/families, highlighting the need to further investigate relationships among DEEs, disruptive sleep, and QoL

Abbreviations: ADL, activity of daily living; DEE, developmental and epileptic encephalopathy; QoL, quality of life.

Results

- In total, 524 responses were collected; 489 responses were included
 - Excluded: Responder did not consent (n=3), was not a caregiver to a patient with rare epilepsy or DEE (n=26), reported a nonqualifying disorder (n=5), or was a duplicate (n=1)
- The median age at DEE diagnosis was 3 years (0–64); at the time of the survey, median age was 8 years (0.2–67)
- The majority of respondents were located in North America (Canada, n=21; Mexico, n=2; United States, n=359)
- Sleep was unpredictable in 47 (9.6%) individuals with DEE (Figure 1)

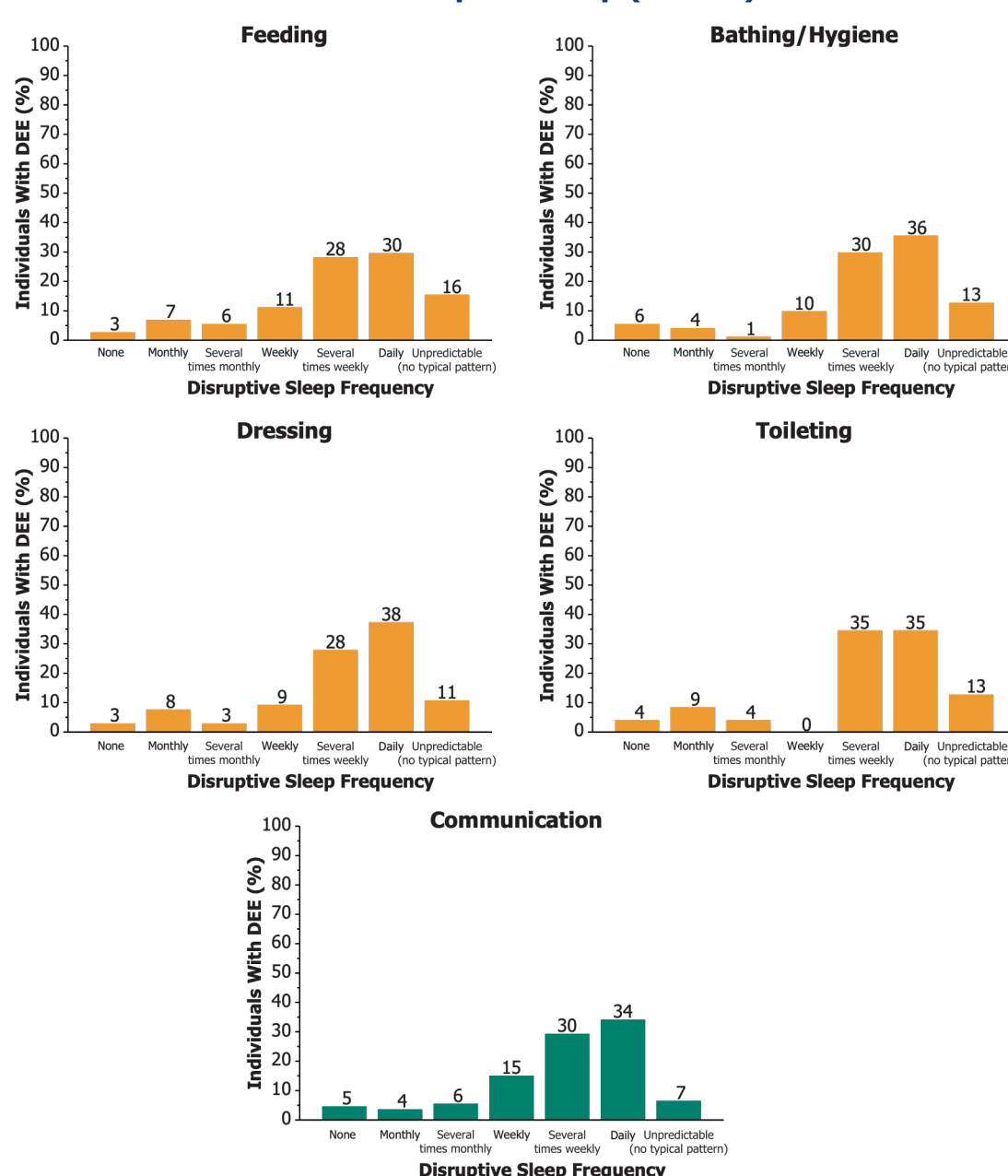
Figure 1. Disruptive Sleep Frequency in Individuals With DEE (N=489)



DEE, developmental and epileptic encephalopathy.

- Sleep disruptions were associated with temporary loss of ≥1 ADL (120/489, 24.5%) and in communication (105/489, 21.5%)
- Some caregivers who reported a temporary loss of an ADL (2.8%–5.7%) or communication (4.8%) due to sleep disruptions also reported that the individual with DEE did not have disruptive sleep (Figure 2)

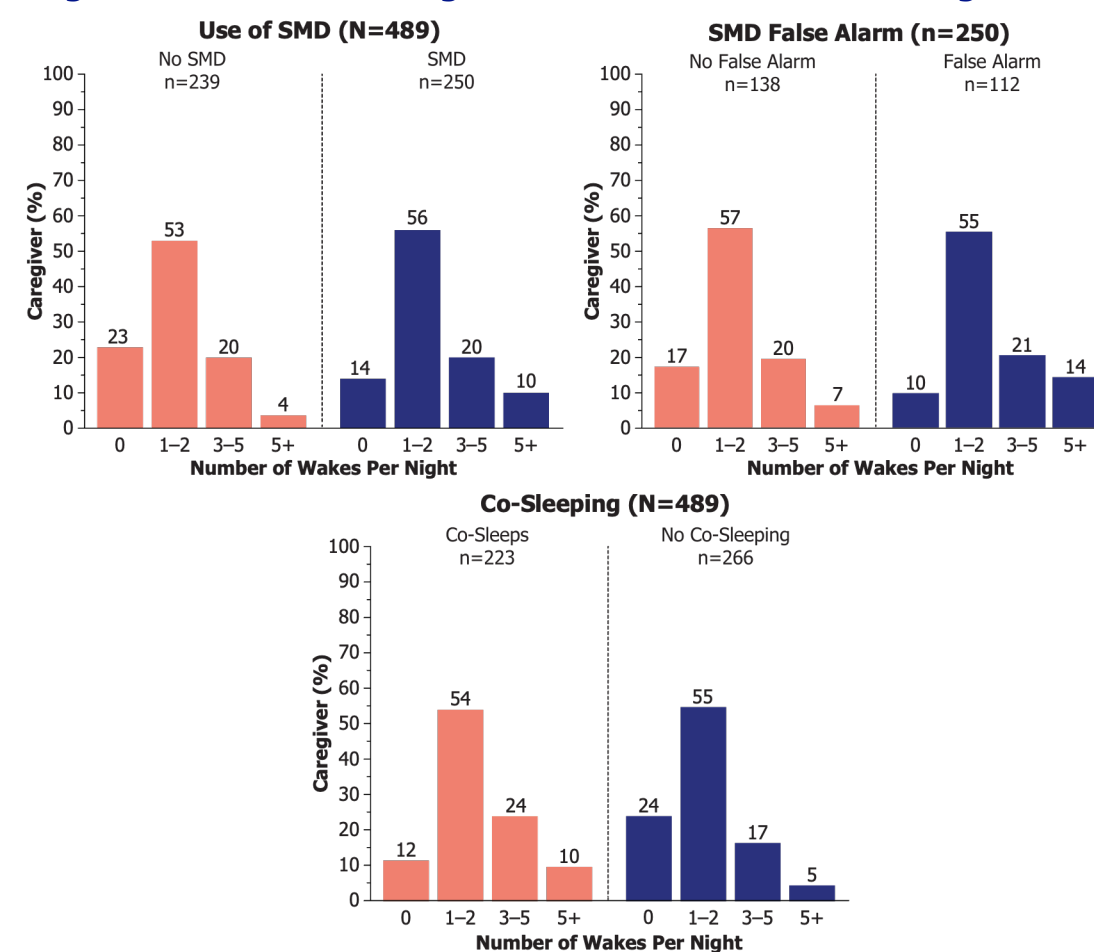
Figure 2. Caregiver-Reported Temporary Loss of an ADL or Communication Due to Disruptive Sleep (N=489)



ADL, activity of daily living; DEE, developmental and epileptic encephalopathy.

- Approximately half (250/489; 51.1%) of caregivers reported using a surveillance or SMD for nighttime use; of these, 112 (44.8%) reported SMD false alarms
- Nearly half (223/489; 45.6%) of caregivers reported that the individual with DEE co-sleeps at least occasionally
- Regardless of the use of an SMD, the occurrence of SMD false alarms, or co-sleeping status, caregivers experienced a similar frequency of nightly sleep disruptions (Figure 3)

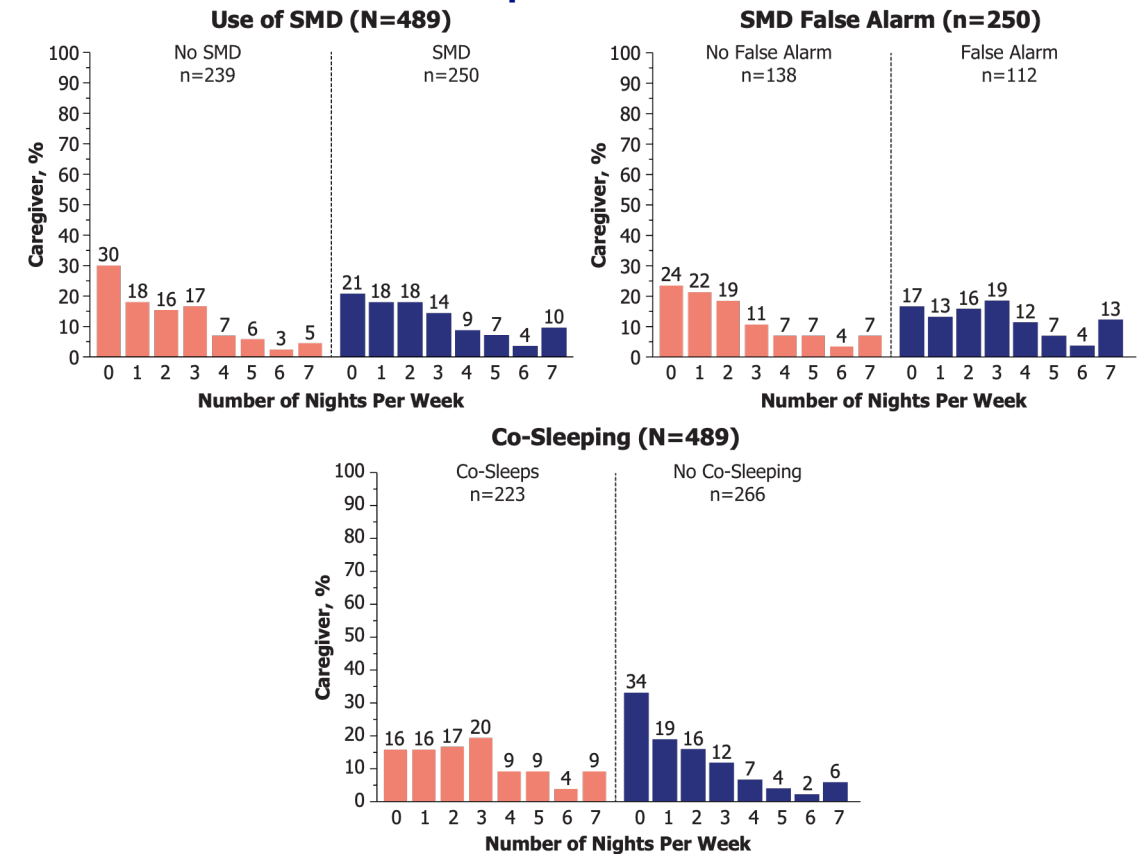
Figure 3. Number of Caregiver Wakes >30 Minutes Per Night



SMD, seizure monitoring device.

- Regardless of the use of an SMD, caregivers reported waking and being unable to get back to sleep at similar frequencies per week (Figure 4)
- Fewer caregivers who reported the occurrence of an SMD false alarm experienced 0 nights of disrupted sleep per week than those who used an SMD with no false alarm occurrences
- A greater proportion of caregivers who reported that the individual with DEE did not co-sleep experienced 0 nights of disrupted sleep per week than those who reported co-sleeping

Figure 4. Number of Nights Per Week the Caregiver Wakes and Is Unable to Get Back to Sleep



SMD, seizure monitoring device.

- The most commonly reported cause of excessive day and/or night sleeping in the individuals with DEE was medication side effects (33.5%), followed by daytime (27.2%) and nocturnal seizures (26.8%)
- Medical device side effects were reported as a cause of excessive day and/or night sleep by 2.2% of caregivers
- Approximately 5% of caregivers reported that daytime sleep due to medication side effects or postictal periods had a severe impact on nighttime sleep
- Medication side effects (23.3%) and postictal periods (28.6%) had a moderate impact on sleep as reported by caregivers

Conclusions

- Approximately 70% of caregivers reported that the individual with DEE experienced disruptive sleep at least weekly
- Sleep disturbances were reportedly associated with temporary loss of an ADL or communication in approximately a quarter of individuals with DEE
- Disruptive sleep may represent a modifiable factor influencing QoL in individuals with DEE and their families
- The role of contributors to sleep disruptions, including sleeping habits per age group, in individuals with DEE should be further examined

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