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Introduction

Children with cerebral palsy (CP) are four times more likely to experience sleep disturbances than their typically developing peers¹. Sleep plays a critical role in a child's learning, physical growth and psychological wellbeing. Unresolved sleep disturbances have been found to impact the child with CP and their family^{2,3}. However, to date, the nature or extent of sleep disturbances for children with CP living in Northern Ireland has not been investigated.

Aims

1. To describe the **prevalence and nature** of sleep disturbances experienced by children with CP in Northern Ireland (NI); and
2. To explore **parent perceptions** of sleep disturbances within the family.

Patients and Methods

Procedure: Parents of children with CP aged 3-18 years resident in NI completed an online questionnaire that included the Sleep Disturbance Scale for Children⁴ (SDSC; higher score indicates greater sleep disturbance), and questions relating to their child's CP and family sleep.

Data Analysis: Prevalence of overall clinical sleep disturbance and specific sleep disorders (as measured by SDSC subscale scores) were analysed descriptively. Clinical sleep disturbance was defined as a SDSC total raw score of $\Rightarrow 51$ (using the original Bruni et al. (1996) norms⁴) or a total raw score $\Rightarrow 65$ (using the more recent Jacquier & Newman (2019) norms⁵). Sample characteristics were compared with the NI CP register to ascertain representativeness.

Results

Of the 112 submitted responses, 111 were valid for analysis. The sample was 63% male; 62% had spastic CP and 37% were classified as GMFCS IV-V. Sample characteristics were not significantly different to an age-matched cohort known to the NI CP register, except by age whereby the sample was significantly younger ($p < 0.001$; mean age 8.8 years vs NI CP register mean age for same birth years was 12.7 years).

Prevalence of sleep disturbances

Prevalence of clinical sleep disturbance for children aged 3-18 years in Northern Ireland **ranged from 43% to 74%** depending on definition of clinical sleep disturbance applied.

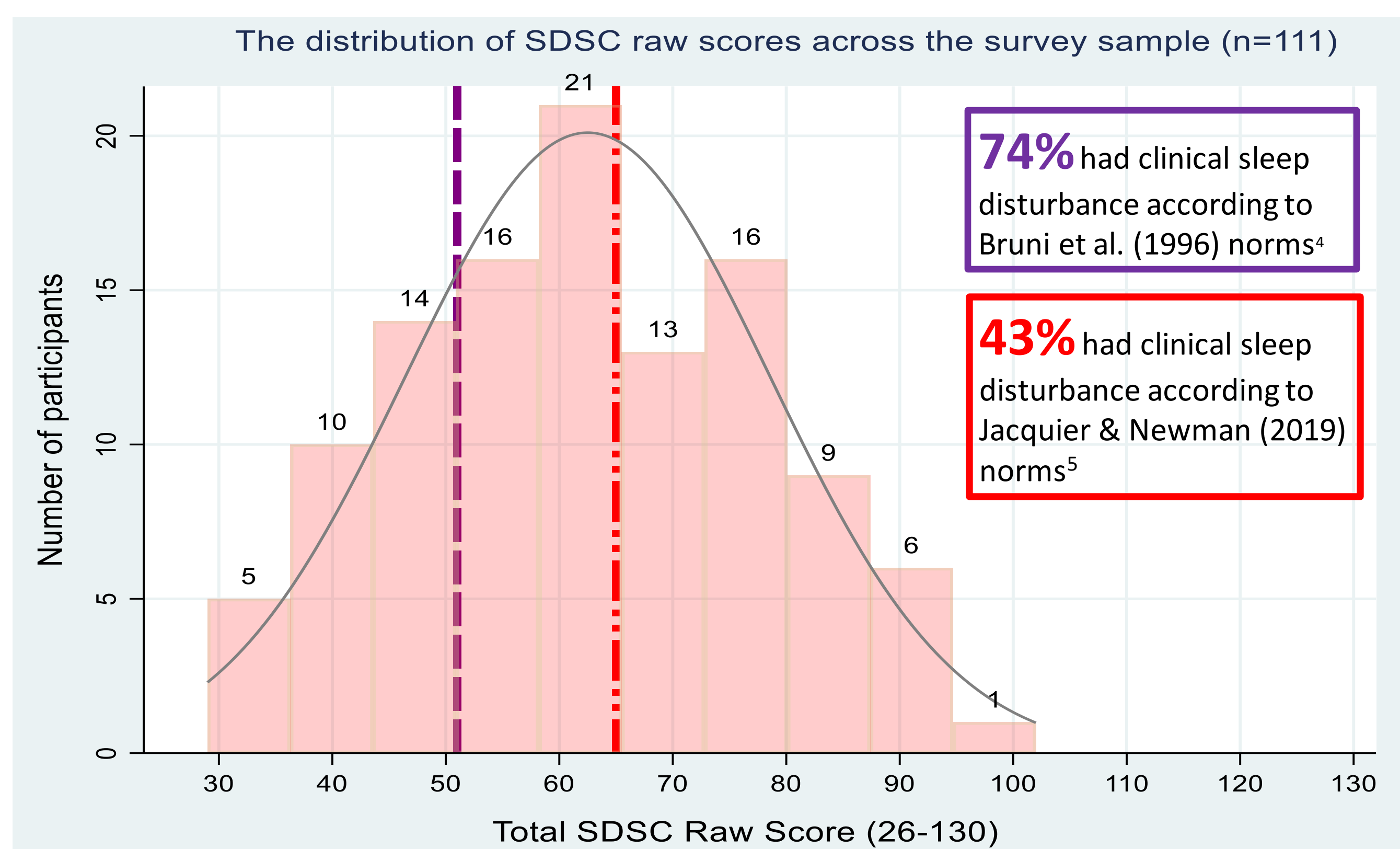


Figure 1 displays the frequency distributions for participants' total raw scores on the SDSC (available range: 26-130). The purple dashed line on the left displays the cut-off for a clinical sleep disturbance according to the Bruni et al. SDSC norms⁴ and the red dashed line on the right displays the cut-off for a clinical sleep disturbance according to the Jacquier & Newman SDSC norms⁵.

Nature of sleep disturbances experienced

As a result of the very high total SDSC scores, the proportion of children experiencing clinical sleep disturbance in each of the SDSC subscales was also similarly high as shown in Table 1 below. In particular, almost half the sample had a clinical level of sleep disturbance in **Disorders of Initiating and Maintaining Sleep** e.g. insomnia.

Table 1. The proportion of the survey sample experiencing sleep disorders compared to the general population and children with a motor disability using Jacquier & Newman (J&N; 2019) SDSC norms⁵.

SDSC Subscale	Proportion with clinical sleep disturbance based on Jacquier & Newman (2019) norms ⁵ .		
	Survey sample (n=111)	J&N population norms (n=2891)	J&N disability norms (n=245)
Disorders of Initiating and Maintaining Sleep	47.7%	2.2%	8.9%
Sleep-Wake Transition Disorders	27.9%	2.1%	6.6%
Disorders of Excessive Somnolence	25.2%	2.0%	7.7%
Sleep Hyperhidrosis	23.4%	1.1%	3.3%
Sleep Breathing Disorders	19.8%	2.0%	9.9%
Disorders of Arousal	18.0%	2.0%	2.6%
Total Score	43.2%	1.9%	7.0%

Parent perceptions of sleep disturbances within the family

Parents reported that pain (53%), difficulty changing position in bed (34%) and epilepsy (20%) most impacted their child's sleep. Most parents felt their sleep was affected by their child's sleep (86%). Almost three quarters of parents slept less than 7 hours per night (70%), 52% provided night-time support to their child with CP and just under a third shared a bed with their child (38%). Sibling sleep disturbance was reported by 38% of parents, with 6% of siblings being involved in night-time support.

Conclusion

The **prevalence of sleep disturbances experienced by children with CP in NI is very high**. Further investigation of the impact of sleep disturbances on these children and their families, as well as establishment of dedicated support services, are recommended.



References

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