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Step-By-Step Approach in Managing Sleep Problem in Children with Intellectual Disability

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Introduction

Sleep problem in children with intellectual disability (ID) is commonly reported in the literature [1-3], yet high quality evidence on its management is scarce. Nonetheless, this problem causes great stress from the carer and directly affects the children's quality of life. As part of the collaboration project by a local hospital and a special school for ID children, we have designed the following step-by-step approach in tackling the problem, especially in the setting of institutions with or without hostel residency, which yield very positive feedback from the special schools.

Five Steps Approach in Management

Step 1: We must emphasize the first step of management is correct identification of children with sleep disorders, and those with risk factors should receive extra attention. Children with ID are already a high risk group for developing sleep disorders we propose all of them should be routinely screened. This can be in form of standardized questionnaire such as Children's Sleep Habits Questionnaire (CSHQ) [4]. CSHQ consists of 33 scored items, which can take 15-20 minutes to complete by the care-taker. It covers different sleep disorders, is easy to be administered by care-taker, and consists of a cut-off point with good sensitivity and specificity. In our experience, we had been using the Chinese version of CSHQ [5] filled in by both the parents and hostel staff, with cut-off point of 41 to stratify all the students of the school into high and low-risk groups. A significant portion of high-risk students turned out to have sleep disorder diagnosed eventually. We were planning to use CSHQ as part of the health assessment, such as during intake of new students or at the start of each academic year to identify the high-risk students.

Step 2: Screening itself only identifies the possibility of a sleep disorder. The correct diagnosis requires further information. For example, detailed history especially complaints from the care-taker, developmental and family history, sleep diary and physical examination may be required to establish a diagnosis. Certain differential diagnoses should also be taken into account. Abnormal movement during sleep may represent some forms of parasomnias or epileptic seizure (such as nocturnal frontal lobe epilepsy) [6]. In our experience, we had involved an advanced practice nurse from our hospital to intake all the high-risk group identified in the first step,

so as to channel and triage them to appropriate disciplines including respirologist, sleep specialist or neurologist for the purpose of diagnosis. In the hospital setting, further investigations such as video electroencephalogram or polysomnography were required in selected cases. We must also take note of the co-morbidities of the children, such as co-existing epilepsy and obesity, as they are shown to increase the risk in developing certain sleep disorders [7-10]. These co-morbidities should be sought out and adequately managed. For example, snoring or excessive daytime sleepiness in an obese child should prompt the need for assessment by a sleep specialist and polysomniography to look for any sleep disordered breathing. Children with these conditions should have their seizure and body weight optimized as part of the management of their co-morbidities.

Step 3: General principles of sleep hygiene should apply to all children, but more importantly in children diagnosed with sleep disorders. We suggest that institutions especially boarding schools should initiate measures to promote good sleep habits for their students, and high risk subjects such as those with co-morbid epilepsy should receive more attention with regard to their sleep issue. It was shown that these measures can significantly improve the sleep in people with ID living in residential setting [11]. Fundamentals of good sleep hygiene include: Firstly, to provide a good sleeping environment, such as a familiar, darkened, quiet, non-stimulating room with correct temperature and comfortable bed. Secondly, to encourage regular daytime and bedtime routines and timing, such as consistent bedtime and wake-up time. Thirdly, to avoid stimulating items before bed, such as caffeine-containing drinks and arousing activities [12,13]. In our experience, these measures needed to be slightly modified

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to fit into the setting of special schools especially with hostel residency. We advised the school to have a regular timetable for students' wake-up and bedtime. Students should avoid stimulating activities such as watching television or vigorous learning activities during lesson just prior to their sleep time. Special arrangements were to be made for the triaged highrisk students, such as to nurse them in a quieter, darker corner of the hostel to provide a better sleeping environment for them.

Step 4: A number of behavioural sleep interventions were described in the literature, in particular for children with ID. They had different approaches to the common sleep problem, such as improving the sleep quality, sleep-wake schedules and sleep regularity. In a review article, 90 studies involving children with developmental disability undergoing non-pharmacological sleep management were identified, it was concluded that over 70% of them reported success [14]. Examples such as multi-section structured program with homework task [15], or behavioural treatment with structured interview, active monitors and questionnaires [16] all showed success in improving sleep problem in this group of children. Even a booklet delivering behavioural treatment for sleep problems was shown to be as effective as face-toface treatment for children with ID [17]. In our experience, certain behavioural sleep interventions for students with sleep disorders should be tailor-made taking into account of different types and severity of sleep disorders, level of ID and the resources. Those with minor problem can be given a booklet with brief interview to the care-taker, and structured multi-section program is required for problematic subjects, though standard programs may need modification to fit different children with special needs.

Step 5: Different pharmacological agents have been shown to improve sleep in children with ID. Melatonin, a natural substance secreted from the pineal gland, has gained recent popularity in management of sleep disorders, especially those related to sleep-wake cycle. Its efficacy has been studied and it shows a significant treatment effect on sleep latency in subjects with ID and epilepsy. It is well tolerated and no side effects or effect on seizure frequency were reported [18]. In our experience, we put the use of pharmacological agents as our last resort, after the non-pharmacological measures had failed. Partly because many parents initially showed reluctance to use medication before other measures were tried, and also we noticed that coupling with non-pharmacological approaches in the steps above appeared to have some "synergistic" effect with use of pharmacological agents, as compared with prescription alone. Appropriate case selection was also important, as we found melatonin to be more useful in those with sleep problems related to circadian rhythm disorders. It was also important to take note of the concomitant use of medication especially anti-convulsants, as different side effect profile of the medication may affect the sleep in these children.

Conclusion

Management of sleep problem in children with ID involves multi-steps approach and collaboration between dif-

ferent disciples. To start with, a good screening program and identification the correct diagnosis of sleep disorders are paramount, followed by implementation of non-pharmacological approach, ensuring good sleep hygiene and tailor-making special program in some cases. Pharmacological agents would be considered in selected cases, taking into account the underlying sleep disorders and co-morbidities.

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Conflict of Interest

The author declares no conflict of interest.

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