



Systematic Review

# Sleep Assessments for Children With Severe Cerebral Palsy: A Scoping Review



Jennifer A. Hutson, PhD, OTR/L, ATP <sup>a,b</sup>,  
LeAnn Snow, MD, PhD <sup>c</sup>

<sup>a</sup> Department of Occupational Therapy, St. Catherine University, St. Paul MN

<sup>b</sup> Orthotics, Prosthetics and Seating Department, Gillette Children's Specialty Healthcare, St. Paul, MN

<sup>c</sup> Division of Rehabilitation Science, Department of Rehabilitation Medicine, University of Minnesota, Minneapolis, MN

## KEYWORDS

Cerebral palsy;  
Patient outcome  
assessment;  
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Rehabilitation;  
Sleep;  
Supine position

**Abstract Objectives:** To identify the sleep-based instruments in postural care intervention research and examine whether the instruments are suitable as postural care outcome measures specifically for children with severe cerebral palsy.

**Data Sources:** Investigators searched the electronic databases from 2 university library systems, including OVID Medline, CINAHL, OT Search, Cochrane Database of Systematic Reviews, and Health and Psychosocial Instruments for articles published between 2000 and October 2019.

**Study Selection:** The initial search yielded 1928 abstracts. Two independent investigators identified 8 English-language peer-reviewed articles that published postural care intervention study results.

**Data Extraction:** Investigators screened the 8 articles and found that 6 included sleep as a primary or secondary intervention outcome. The principal investigator then fully reviewed these 6 publications, recorded their sleep-related instruments, and applied Coster's published guidelines (2013) to analyze the sleep-based instruments' suitability as outcome measures.

**Data Synthesis:** Collectively, the 6 studies used 8 distinct measures, 6 of which (actigraphy, Chailey Sleep Questionnaire, Pediatric Sleep Questionnaire, polysomnography, sleep diary, and Sleep Disturbance Scale for Children) underwent analysis. As stand-alone instruments, none completely met criteria for suitability as outcome measures for those with severe cerebral palsy.

**Conclusions:** Combined use of the Sleep Disturbance Scale for Children and actigraphy may be favorable for assessing the sleep-related domains relevant to children with severe cerebral

**List of abbreviations:** COSMIN, COnsensus-based Standards for the selection of health status Measurement Instruments; CP, cerebral palsy; CSQ, Chailey Sleep Questionnaire; GMFCS, Gross Motor Function Classification System; PSQ, Pediatric Sleep Questionnaire; SD, sleep diary; SDSC, Sleep Disturbance Scale for Children; SDSC-R, revised version of the Sleep Disturbance Scale for Children.

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palsy. However, rehabilitation professionals should test sensitivity and specificity to understand the instruments' ability for capturing changes in sleep from postural care intervention. © 2020 The Authors. Published by Elsevier Inc. on behalf of the American Congress of Rehabilitation Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Children with severe cerebral palsy (CP) have significant sleep-related problems.<sup>1-3</sup> Common disturbances include issues of sleep initiation, maintenance, breathing, sleep-wake transition, daytime sleepiness, and total sleep time.<sup>1,2</sup> These sleep disturbances occur more often and begin earlier (eg, at the age of 3-5y) for children with CP compared with other children.<sup>2,3</sup> In addition, these disruptions are significantly associated with the severity of CP.<sup>3,4</sup> This means that those at levels IV and V on the Gross Motor Functional Classification System (GMFCS) have the greatest sleep disturbances.

Given the pervasiveness of these sleep-related problems, rehabilitation professionals need to know whether their interventions affect sleep. Multidisciplinary experts recommend nighttime postural care for those at all GMFCS levels, and they recommend the intervention "as soon as possible after birth" for those with severe CP (GMFCS IV and V).<sup>5</sup> Because this intervention takes place at the time of sleep and uses positioning systems for whole-body support, it has the potential to affect a child's sleep function. Rehabilitation professionals can only understand the effect of nighttime postural care if they administer outcome measures capable of capturing sleep-based changes.

Authors of previous studies have stated that sleep problems among children with CP are under-recognized and under-reported, which suggests that many rehabilitation professionals are not evaluating sleep.<sup>6,7</sup> In addition, those who do assess and reassess sleep may fail to appropriately identify intervention changes because they use nonstandardized measures or choose instruments that are irrelevant to a specified intervention or population.<sup>8-11</sup> This problem of inappropriately choosing sleep-based assessments occurs both clinically and during intervention research.<sup>10,11</sup> Although previous investigators have examined the psychometric properties of existing sleep-based assessments,<sup>12</sup> none have addressed whether such measures are capable of capturing sleep-related changes for children with severe CP receiving postural care interventions. Investigators must conduct further examinations of these sleep-based instruments so rehabilitation professionals can make appropriate choices when selecting outcome measures.

Investigators typically apply systematic criteria such as the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) Risk of Bias Checklist or Coster's guiding questions when critiquing outcome measures. Although the COSMIN Risk of Bias Checklist is well known, it is designed for examining the psychometric properties of patient report instruments.<sup>13</sup> Coster's published criteria,<sup>9</sup> on the other hand, can be used with a variety of measurement tools and help investigators determine the instruments' fit with a specified population and intervention. Because both caregiver report and biometric devices have been used by postural care interventionists to assess sleep,

Coster's guiding questions may be more appropriate than the COSMIN checklist when critiquing sleep-based instruments.

Those applying Coster's guiding questions<sup>9</sup> use a series of "who," "when," and "how" questions to determine whether an instrument is useful for capturing intervention changes. Some "who" questions include: If someone other than a professional will be the respondent, is it probable [they] will be able to complete the assessment, and Will identified respondents be available throughout the study [intervention] period.<sup>9</sup> Some "when" questions include: Does the length of time between assessments match the time over which the instrument is likely to show effects, and Can the measure be administered as often as required.<sup>9</sup> Some "how" questions include: Does the instrument address the relevant domains of greatest importance and its dimensions reflect the type of change expected from the intervention, Is the measure sensitive to the degree of change expected for this population, and Are item and scale wording appropriate (eg, meaningful, understandable) for this population.<sup>9</sup> This study discusses results of a scoping review that applies Coster's questions.

This scoping review aims to (1) identify the sleep-based instruments used in postural care clinical intervention research, (2) critique the instruments based on their suitability as postural care outcome measures specifically for children with GMFCS IV and V CP, and (3) make outcome measure recommendations. We define this scoping review as an in-depth coverage of a particular concept based on existing gaps in the literature.<sup>14</sup>

## Methods

### Eligibility and ethics

Investigators (J.A.H.) deemed articles as meeting eligibility criteria if they were English-language full-length peer-reviewed original (postural care) research articles in which sleep was identified as a primary or secondary outcome. Investigators searched publications dated from 2000 to October of 2019, knowing that 2000 was the first year in which nighttime postural care intervention results were published. Investigators excluded systematic reviews, except to confirm exhaustive search, and studies measuring exclusively sleep apnea. This review did not involve human subjects and received no funding.

### Search methods

Two investigators (J.A.H.) independently conducted searches between January and May 2018. One of the investigators (J.A.H.) conducted an additional search in October 2019 across 2 university library systems using the

following databases: Medline/PubMed, CINAHL, OT Search, Cochrane Database of Systematic Reviews and Health, and Psychosocial Instruments, using keywords and boolean operators (eg, AND, NOT). Titles and abstracts were then screened based on the inclusion and exclusion criteria. Primary keywords included: sleep, sleep measures, cerebral palsy, night postural management, night positioning equipment, sleep orthosis, postural care, and sleep systems. Investigators also conducted author and citation searches and reviewed the published reference lists of known postural care authors.

## Analysis method

The principal investigator (J.A.H.) methodically applied Coster's questions,<sup>9</sup> determining each sleep-based instrument's suitability as an outcome measure for use in children with GMFCS IV and V CP. The examination entailed an iterative process of reviewing Coster's questions,<sup>9</sup> published literature about each measure (eg, psychometric studies), articles on sleep in children with CP, and postural care intervention research. Additionally, the investigator contacted published authors when deemed necessary for proceeding with analysis.

## Results

### Search results

Search of "sleep assessments AND postural care" revealed 1928 articles, most of which were irrelevant. A further Medline/PubMed search of "cerebral palsy and night postural management NOT sleep apnea NOT systematic

review" revealed 64 results. From these abstracts, we found 9 articles that specifically addressed nighttime postural care. However, some were review articles and one was written in French (with only the abstract in English). Five of these publications included results of original research examining the effect of nighttime postural care. We found 3 additional publications after reviewing bibliographies, thus resulting in a total of 8 original research studies on the effect of nighttime postural care.<sup>4,15-21</sup> Investigators had no discrepancy about including these 8 articles for full review.

After fully reviewing these 8 articles, we found 6 that used sleep as a primary or secondary outcome.<sup>4,15-18,21</sup> We excluded one of these publications because there was little detail about their sleep assessment.<sup>16</sup> Therefore, we ultimately included 5 publications (table 1). Collectively, these 5 studies used low to medium level designs; 3 were experimental studies (2 cross-over, 1 single-subject longitudinal), 1 was quasi-experimental, and 1 was descriptive.<sup>4,15,17,18,21</sup> From these studies, we analyzed 6 sleep-based instruments (4 caregiver report and 2 biometric monitoring devices), 3 of the instruments were used by the postural care researchers as outcome measures (see table 1),<sup>17,18,21</sup> The 6 instruments included actigraphy, Chailey Sleep Questionnaire (CSQ), Pediatric Sleep Questionnaire (PSQ), polysomnography, sleep diary (SD), and Sleep Disturbance Scale for Children (SDSC) (table 2).

### Critical analysis

As suggested by Coster,<sup>9</sup> before sharing results, we will discuss intervention-related expectations (eg, postural care) and the complexities of the specified outcome being

**Table 1** Original postural care research study description and sleep-based instruments

Study	Study Description	Outcome	Sleep-Based Instrument
Dawson et al <sup>15</sup>	Quasi-experimental, children with severe motor disorders (n=13) compared with typically developing controls (n=12)	Sleep-disordered breathing, ventilatory function	Sleep diary
Hankinson and Morton <sup>17</sup>	Experimental single-subject longitudinal (n=11)	Hours asleep	Sleep diary*
Hill et al <sup>18</sup>	Experimental cross-over, randomized order, one night with/without sleep system (n=10)	Sleep quality	Polysomnography* Pediatric Sleep Questionnaire
Mol et al <sup>4</sup>	Descriptive cross-sectional questionnaire study, night orthoses users (n=55) compared with non-users (n=27)	Sleep disturbance	Sleep Disturbance Scale for Children
Underhill et al <sup>21</sup>	Experimental cross-over, randomized order, 4 nights with/without sleep system (n=11)	Sleep quality	Actigraphy* Chailey Sleep Questionnaire Sleep diary Interview

\* Indicates that postural care researchers used that instrument for outcome measurement. Instruments without an asterisk were used at initial assessment but not reassessment.

**Table 2** Description of 6 sleep measures included for analysis

Name	Description	Type
Chailey Sleep Questionnaire	36-item clinical profile and 35-item sleep profile to guide intervention of children GMFCS III to V <sup>24</sup>	CR
Pediatric Sleep Questionnaire	22 items for examining presence of sleep-related breathing disorder, daytime sleepiness, and other behaviors in children <sup>18,25</sup>	CR
Sleep Disturbances Scale for Children	26 items to evaluate sleep disturbances from past 6 months, including sleep initiation/maintenance, breathing, arousal, transitions, daytime sleepiness, and sweating in children <sup>19</sup>	CR
Sleep diary	Several weeks' nightly record of sleep activity, typically time to bed, time to sleep, night waking, overall sleep time <sup>24,29</sup>	CR
Actigraphy	Wearable accelerometer that tracks rest and activity cycles via gross motor movement <sup>24</sup>	BD
Polysomnography	Test conducted in clinic to diagnose sleep disorder by recording brain waves, blood oxygen, heart rate, breathing, eye and leg movements <sup>23</sup>	BD

Abbreviations: BD, biometric monitoring device; CR, caregiver report.

measured (eg, sleep disruption). Regarding the intervention, if nighttime postural care produces its desired effect, rehabilitation professions might expect the child to experience reduced sleep-related disruptions. In addition, given both the complexity of sleep itself and the processes surrounding night positioning,<sup>16</sup> it is most realistic to believe these changes would occur over a period of months. Although some intervention recipients may demonstrate immediate sleep-related changes (eg, those who readily adjust to the supported sleep position and feel pronounced pain reduction), others would require a period of adjustment and time for body systems to respond once routine sleep-system use is achieved. Regarding the construct of sleep, the literature tells us that children with severe CP have sleep disruptions crossing many domains.<sup>1,2</sup> These domains include difficulty with sleep initiation and maintenance, alteration in sleep-wake transition, occurrence of sleep breathing disorders, increases in daytime sleepiness, and decreases in total sleep time.<sup>1,2</sup> Therefore, to be considered a good match to the specified intervention and client population, we suggest a minimum requirement that the sleep-related instrument be sensitive to change that occurs over a period of many months, and that it be capable of assessing the aforementioned sleep-related issues.

## Communicating results

This paper's authors incorporate green-, yellow-, and red-light rankings to clearly communicate each measure's suitability. The color rank meanings, modified from previous studies,<sup>22</sup> are as follows: green represents "good enough" or "having minor problems in comparison to other instruments"; yellow represents "mostly adequate" or "need for further development or testing"; and red represents "inadequate or inappropriate." Rankings are meant to show whether the identified sleep-based instruments meet criteria as outcome measures for children with severe CP receiving postural care interventions.

After examining 6 sleep-related instruments, none individually met Coster's<sup>9</sup> collective "who," "when," and "how" criteria. Some were capable of capturing sleep-related changes based on "who" and "when," but none met criteria on "how" the measure is used (fig 1).

## Instrument rankings

### Who criteria

The "who" criteria primarily address whether assessment administrators have the necessary qualifications.<sup>9</sup> Based on

	Who	When	How
Actigraphy	●	●	●
Chailey Sleep Questionnaire (CSQ)	●	●	NT
Paediatric Sleep Questionnaire (PSQ)	●	●	●
Polysomnography	●	●	NT
Sleep diary (SD)	●	●	●
Sleep Disturbance Scale for Children	●	●	●

Note. ● = green-light ranking; ● = yellow-light ranking; ● = red-light ranking; NT = criteria not assessed.

**Fig 1** Ranking for each instrument according to the who, when, and why criteria.

these criteria, all 6 instruments received green-light rankings (for English-language users).

Caregiver report instruments received green-light rankings based on their ease of use. For example, the PSQ developers reported creating simple concise items and making revisions after pilot testing, and the SDSC developers stated that they removed items not understood by mothers after pilot testing.<sup>23,24</sup> In addition, the CSQ designers reported having incorporated simple language and a glossary into their instrument.<sup>25</sup> Additionally, the SDs reportedly required the recording of information typically understood by caregivers (eg, time to sleep, time awake, sleep duration, etc). Because instrument developers either changed items in response to caregiver testing or included familiar language, they received a green light on Coster's "who" criteria.<sup>9</sup>

Monitoring devices received green-light rankings because their administration requires either credentialing or minimal skills. For example, polysomnography users undergo administrator credentialing (eg, Registered Polysomnographic Technologist) and actigraphy users generally need only to follow basic instructions about device wear or removal.<sup>26,27</sup> Although not specifically discussed in studies on the effect of postural care,<sup>18,21</sup> it is reasonable to expect that technicians and caregivers could obtain the skills necessary for device use, making administration requirements a "good enough" match to the skills of device users.

#### When criteria

The "when" criteria relate to whether the instrument is administered at times when intervention changes are expected to occur for the given population<sup>9</sup> (eg, sleep-related postural care changes for children with severe CP). On these criteria, the investigator (J.A.H.) gave green-lights to the SDSC, SD, and actigraphy, a yellow-light to the PSQ, and red-lights to polysomnography and the CSQ.

The SDSC, SD, and actigraphy can be administered at times by which sleep-related postural care changes would occur while also accounting for night-to-night sleep variations typical of those with severe CP. The SDSC is meant for administration in 6-month periods,<sup>24</sup> timing that likely allows for sleep-related changes to take effect. SD and actigraphy could be scheduled and data recorded at preferred intervals throughout intervention. In addition, actigraphy allows for continuous data collection throughout intervention, without presenting undue caregiver burden. Given the timing of use, these instruments are a "good enough" match for children with severe CP based on "when" the instruments are used for data collection.

The PSQ receives a yellow-light, deemed "partially adequate," given its time-point of administration and unknown capacity for capturing change over time. The PSQ assesses symptoms over a 1-month period, which may allow for some, but not most, children's sleep-related changes and would likely present undue burden for caregivers if asked to administer every month over a period of months to years. Additionally, studies thus far have primarily examined its use as a diagnostic tool or predictor of postsurgical (adenotonsillectomy) improvement, not for measuring changes over time.<sup>18,23,28</sup> Given these timing factors, the PSQ receives a yellow-light on "when" related criteria.

Both polysomnography and the CSQ received red-light rankings because they are not designed for long-term

tracking. Polysomnography, valuable for initial diagnosis, only accounts for sleep at a moment in time and thus cannot capture night-to-night variations or represent a child's typical sleep. Additionally, its cost prohibits use by clinicians assessing sleep at various intervention intervals. Like polysomnography, the CSQ is most useful for initially identifying sleep problems. The instrument's developers designed the assessment to pinpoint sleep problems and guide clinical intervention, not to capture intervention changes.<sup>21,29</sup> Because polysomnography and the CSQ were given red-light ratings as outcome measures, the criteria of "how" will only be applied to the PSQ, SD, actigraphy, and the SDSC.

#### How criteria

The "how" criteria primarily relate to the match of the instrument's domains and items to the population and the appropriateness of its sensitivity and specificity.<sup>9</sup> In this context, sensitivity refers to the instrument's ability to detect sleep disruption or disorder, and specificity refers to the instrument's ability to detect absence of sleep disruption or disorder. Based on these criteria, the PSQ and SD received red-light rankings, whereas actigraphy and SDSC received yellow-light rankings.

Instruments receiving red-light rankings are those addressing no more than 2 of the 5 sleep domains important for children with severe CP (domains of sleep initiation and maintenance, sleep-wake transition, sleep breathing, daytime sleepiness, and total sleep time) or those containing many irrelevant items. The PSQ addresses only 2 of the identified domains (sleep apnea and daytime sleepiness), and 8 of its 22 items are not relevant to children with severe CP (eg, items like fidgets, on the go, interrupts, and has obesity). SDs also miss important domains. Although they address sleep quality, they cannot measure nocturnal epilepsy and obstructive sleep apnea.<sup>30</sup> For these reasons, the PSQ and SD received red-light rankings.

Actigraphy and SDSC received yellow-light rankings and were considered as "mostly adequate" based on having relevant items that address more domains than the other instruments, while still needing further testing. Actigraphy measures sleep-quality and nocturnal epilepsy, missing only the domain of obstructive sleep apnea. The SDSC measures sleep quality and sleep-related breathing issues, but not nocturnal epilepsy.<sup>30</sup> Additionally, all but 3 of the 26 SDSC items (sleepwalking, excessive sweating upon falling asleep, and excessive sweating during sleep) are applicable to children with severe CP.<sup>1</sup> However, both instruments require further testing of sensitivity and specificity. For example, Bruni et al<sup>24</sup> reported good sensitivity and specificity of the SDSC for a clinical population, but children with CP were not part of the study sample (O. Bruni, personal communication, November 19, 2017). In addition, only 1 peer-reviewed publication reported the sensitivity and specificity of actigraphy for children with GMFCS IV and V CP.<sup>31</sup> The instrument's ability to detect sleep also remains unknown, given that investigators examined sedentary versus active states, but not sleep.<sup>31</sup> Although these instruments show relevance to children with severe CP, their ability to differentiate sleep versus sleep disruption requires additional research.

## Interpretation

As stand-alone measures, none of the reviewed instruments can fully capture the anticipated sleep-related postural care intervention changes relevant to children with GMFCS IV and V CP. We recommend that rehabilitation professionals use more than 1 instrument when measuring sleep-related postural care outcomes. Of the instruments reviewed, pairing the SDSC with actigraphy would allow rehabilitation professionals to gather the most relevant domain-specific data over a period of many months.

## Discussion

This scoping review's recommendation for using more than 1 sleep-related measure is consistent with past research. For example, previous authors have stated the importance of supplementing caregiver report with objective measures to account for bias.<sup>32,33</sup> Acebo et al<sup>33</sup> stated that the combined use of actigraphy and SD gives context to actigraphy recordings and helps explain data artifacts. Until other options for understanding sleep-related changes become available, it seems necessary for rehabilitation professionals to continue using multiple sleep-related instruments.

Sleep is one of many outcomes rehabilitation professionals typically examine when evaluating the effect of nighttime postural care. When considering caregiver burden, it would be best if there were a single instrument capable of capturing sleep changes. For example, commonly examined outcomes include musculoskeletal, sensory, and breathing-related functions and number of medical procedures.<sup>4,15-21</sup> Caregivers are often called upon to track progress or be present when clinicians are measuring these outcomes, which demands their time and energy. Because of these factors, rehabilitation professionals must weigh caregiver costs with the benefits of using more than 1 instrument on a particular intervention outcome.

Because actigraphy tracks body movement using accelerometers, it is questionable whether the tool can differentiate sleep and wakefulness, given that children with severe CP rarely initiate position changes while lying.<sup>34</sup> The only study investigating actigraphy in children with severe CP compared uniaxial (tracks movement in 1 axis) to triaxial actigraphy (tracks movement in 3 axes). This study aimed to establish sensitivity and specificity cutoff points for activity versus inactivity.<sup>31</sup> The authors did not examine sleep, but found that triaxial actigraphy (not uniaxial) was valid for those with GMFCS IV and V during waking hours.<sup>31</sup> They also concluded that individuals with GMFCS IV and V, compared with GMFCS I to III, required different cutoff points.<sup>31</sup> Although future studies are needed, these results suggest that triaxial, not uniaxial actigraph, might be appropriate for the identified population.<sup>31</sup> In addition, these results reinforce the idea that rehabilitation professionals' choice of outcome measures for children with severe CP will differ from those of other populations.

Rehabilitation professionals using triaxial actigraphy may miss important data unless they also use SDs. For

example, previous investigators have found that SDs helped to explain sleep movements or disruptions caused by parent handling or data gaps when actigraphy was turned off or not working.<sup>33,35</sup> Given our recommendation that actigraphy be paired with the SDSC to capture all relevant sleep-related domains, SD would be the third instrument used for examining 1 outcome. Rehabilitation professionals need to carefully consider the time schedules by which they use these instruments to ensure that the most important data are collected and to protect caregivers from the potential burden such data gathering presents.

Another factor to be considered is that, although we examined the original SDSC in our scoping review, there now is a more recently published revised version (SDSC-R) that is likely better suited for children with CP. Although past postural care interventionists used the original 26-item English-language SDSC, this version was not validated for individuals with CP (O. Bruni, personal communication, November 30, 2019). However, it is not surprising that postural care interventionists chose the SDSC, given that it is one of the most frequently used sleep-based assessments and is known for having psychometric strengths.<sup>11</sup> Since the time the reviewed postural care studies took place, other investigators have conducted factor analysis on the SDSC.<sup>1</sup> These investigators included children with CP in their study sample, with some even having severe CP (R. Bucks, personal communication, December 17, 2019). To achieve a tool with items relevant for those with CP, Marriner et al<sup>1</sup> ultimately removed 3 of the original items (2 hyperhidrosis, 1 sleep maintenance) and created the SDSC-R. Although the use of the SDSC-R has not yet been applied to research on nighttime postural care interventions, we recommend that rehabilitation professionals consider the SDSC-R over the SDSC because it is the only version validated for children with CP. Additionally, we recommend that investigators continue examining the SDSC-R, specifically including a homogeneous sample of children with GMFCS IV and V CP, because the assessment may test differently for those with severe CP.

## Study limitations

For this scoping review only 1 investigator (J.A.H.) analyzed the sleep-based instruments using Coster's questions.<sup>9</sup> This limitation is owing to several factors. First, formal education in nighttime postural care is scarce in the United States, so there are few fully trained practitioners for this intervention. Second, individuals formally trained in this intervention may not have expertise in its application for the specific client population focused on in this review. The authors of this review invite readers who have such expertise to contribute by assessing the accuracy of this analysis or conducting similar investigations.

Detailed information about each measure's psychometrics is not communicated in this review. This is because psychometric properties are not the primary focus given that past studies have already examined the instruments' reliability and validity. Although some psychometric information is discussed in this review, readers interested in such information should appraise previous publications.

## Conclusions

None of the sleep-based instruments used in past postural care intervention studies meet the criteria as stand-alone outcome measures for use in children with GMFCS IV and V CP. By pairing the SDSC with actigraphy, rehabilitation professionals could assess all sleep-related domains identified as relevant to those with severe CP. This conclusion applies to use of these instruments both in the clinic and in sleep intervention research. However, both instruments require additional specificity and sensitivity testing to understand whether they would capture sleep-related postural care intervention changes for the identified population during reassessment.

## Corresponding author

Jennifer A. Hutson PhD, OTR/L, ATP, Department of Occupational Therapy, St. Catherine University, 2004 Randolph Ave., St. Paul MN 55105. *E-mail address:* jahutson@stkate.edu.

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## References

- Marriner A, Pestell C, Bayliss D, McCann M, Bucks R. Confirmatory factor analysis of the Sleep Disturbance Scale for Children (SDSC) in a clinical sample of children and adolescents. *J Sleep Res* 2017;26:587-94.
- Newman CJ, O'Regan M, Hensey O. Sleep disorders in children with cerebral palsy. *Dev Med Child Neurol* 2006;48:564-8.
- Romeo DM, Brogna C, Musto E, et al. Sleep disturbances in preschool age children with cerebral palsy: a questionnaire study. *Sleep Med* 2014;15:1089-93.
- Mol EM, Monbaliu E, Ven M, Vergote M, Prinzie P. The use of night orthoses in cerebral palsy treatment: sleep disturbance in children and parental burden or not? *Res Dev Disabil* 2012;33:341-9.
- Gericke T. Postural management for children with cerebral palsy: consensus statement. *Dev Med Child Neurol* 2006;48:244.
- Fitzgerald DA, Follett J, Van Asperen PP. Assessing and managing lung disease and sleep disordered breathing in children with cerebral palsy. *Paediatr Respir Rev* 2009;10:18-24.
- Adiga D, Gupta A, Khanna M, Taly AB, Thennarasu K. Sleep disorders in children with cerebral palsy and its correlation with sleep disturbance in primary caregivers and other associated factors. *Ann Indian Acad Neurol* 2014;17:473-6.
- Kielhofner G. *Research in occupational therapy: methods of inquiry for enhancing practice*. Philadelphia: F.A. Davis Company; 2006.
- Coster WJ. Making the best match: selecting outcome measures for clinical trials and outcome studies. *Am J Occup Ther* 2013;67:162-70.
- Ganjikia S, Gansor S. The current status of occupational therapy professionals in addressing the occupation of sleep. In: *Proceedings of the AOTA Annual Conference & Expo; 2015 April 18; Nashville, TN. Bethesda, MD: American Journal of Occupational Therapy; 2015.*
- Horwood L, Li P, Mok E, Shevell M, Constantin E. A systematic review and meta-analysis of the prevalence of sleep problems in children with cerebral palsy: how do children with cerebral palsy differ from each other and from typically developing children? *Sleep Health* 2019;5:555-71.
- Bautista M, Whittingham K, Edwards P, Boyd R. Psychometric properties of parent and child reported sleep assessment tools in children with cerebral palsy: a systematic review. *Dev Med Child Neurol* 2018;60:162-72.
- Mokkink L, Prinsen C, Patrick D, Alonso J, Bouter L, de Vet H, Terwee C. COSMIN study design checklist for patient-reported outcome measurement instruments. Available at: [https://www.cosmin.nl/wp-content/uploads/COSMIN-study-designingchecklist\\_final.pdf](https://www.cosmin.nl/wp-content/uploads/COSMIN-study-designingchecklist_final.pdf). Accessed August 18, 2020.
- Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19-31.
- Dawson NC, Padoa KA, Bucks RS, et al. Ventilatory function in children with severe motor disorders using night-time postural equipment. *Dev Med Child Neurol* 2013;55:751-7.
- Goldsmith S. The Mansfield project: postural care at night within a community setting: a feedback study. *Physiother* 2000;86:528-34.
- Hankinson J, Morton RE. Use of a lying hip abduction system in children with bilateral cerebral palsy: a pilot study. *Dev Med Child Neurol* 2002;44:177-80.
- Hill C, Parker R, Allen P, Paul A, Padoa K. Sleep quality and respiratory function in children with severe cerebral palsy using night-time postural equipment: a pilot study. *Acta Paediatr* 2009;98:1809-14.
- Pountney T, Mandy A, Green E, Gard P. Management of hip dislocation with postural management. *Child Care Health Dev* 2002;28:179-85.
- Pountney T, Mandy A, Green E, Gard P. Hip subluxation and dislocation in cerebral palsy - a prospective study on the effectiveness of postural management programmes. *Physiother Res Int* 2009;14:116-27.
- Underhill J, Bryant E, Pountney T. The effect of sleep systems on sleep-wake patterns and pain levels in nonambulant children and young people with cerebral palsy. *J Assoc Paediatr Chart Physiother* 2012;3:57-64.
- Novak I, Honan I. Effectiveness of paediatric occupational therapy for children with disabilities: a systematic review. *Aust Occup Ther J* 2019;66:258-73.
- Chervin RD, Hedger K, Dillon JE, Pituch KJ. Pediatric sleep questionnaire (PSQ): validity and reliability of scales for sleep-disordered breathing, snoring, sleepiness, and behavioral problems. *Sleep Med* 2000;1:21-32.
- Bruni O, Ottaviano S, Guidetti V, et al. The sleep disturbance scale for children (SDSC) construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. *J Sleep Res* 1996;5:251-61.
- Chailey Heritage Clinical Services. *The Chailey Sleep Questionnaire: North Chailey. East Sussex: Chailey Heritage Clinical Services; 2009.*
- Board of Registered Polysomnographic Technologists. Available at: <https://www.brpt.org/rpsgt/about-the-rpsgt-credential/>. Accessed August 18, 2020.
- Martin J, Hakim AD. Wrist actigraphy. *Chest* 2011;139:1514-27.
- Rosen CL, Wang RH, Taylor G, et al. Utility of symptoms to predict treatment outcomes in obstructive sleep apnea syndrome. *Pediatrics* 2015;135:e662-71.
- Sussex Community NHS Foundation Trust. *The Chailey Sleep Questionnaire*. Available at: <https://www.sussexcommunity.nhs.uk/get-involved/research/chailey-research/books-publications.htm>. Accessed August 18, 2020.

30. Ulate-Campos A, Tsuboyama M, Loddenkemper T. Devices for ambulatory monitoring of sleep-associated disorders in children with neurological diseases. *Children (Basel)* 2017; 5:3.
31. Oftedal S, Bell KL, Davies PS, Ware RS, Boyd RN. Validation of accelerometer cut points in toddlers with and without cerebral palsy. *Med Sci Sports Exerc* 2014;46:1808-15.
32. Meltzer LJ, Walsh CM, Traylor J, Westin AM. Direct comparison of two new actigraphs and polysomnography in children and adolescents. *Sleep* 2012;35:159-66.
33. Acebo C, Sadeh A, Seifer R, Tzischinsky O, Hafer A, Carskadon M. Sleep/wake patterns derived from activity monitoring and maternal report for healthy 1- to 5-year-old children. *Sleep* 2005;28:1568-77.
34. Sato H, Iwasaki T, Yokoyama M, Inoue T. Monitoring body position and motion in children with severe cerebral palsy for 24 hours. *Disabil Rehabil* 2014;36:1156-60.
35. Tsai S, Thomas K. Actigraphy as a measure of activity and sleep for infants: a methodologic study. *Arch Pediatr Adolesc Med* 2010;164:1071-2.