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RESEARCH ARTICLE

Development and preliminary validation of the Sleep Screening for Children and Adolescents with Complex Chronic Conditions (SCAC)

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Summary

Children and adolescents with complex chronic conditions, including those with life-threatening or life-limiting conditions, are a heterogeneous population. Many individuals exhibit sleep abnormalities that are measurable by proxy questionnaires. No suitable instrument to assess the wide range of different complex chronic conditions is currently available. The aim of the present study was to develop a screening tool—the Sleep Screening for Children and Adolescents with Complex Chronic Conditions—to effectively obtain sleep behaviour information in this population. Following a mixed-method design, potential items for the Sleep Screening for Children and Adolescents with Complex Chronic Conditions questionnaire were defined through literature research and expert meetings. In a pre-test with $N = 60$ family and professional caregivers, the items' relevance and comprehensibility as well as the instrument's overall design were assessed. For the main test, $N = 315$ participants were recruited in three tertiary paediatric hospitals. A principal components analysis detected the questionnaire's scales. Item analysis focused on mean values, range, difficulty and discriminatory power. Convergent validation of the Sleep Screening for Children and Adolescents with Complex Chronic Conditions was assessed via correlations between scale items. Most patients had neurological or neuromuscular diseases. Four scales ("Falling and staying asleep", "Sleep-associated respiration and arousal", "Daytime sleepiness" and "Sleep-associated movements") emerged. The item analysis showed satisfactory discriminative power. In the preliminary validation, all scales correlated positively with a child's care level and with various sleep circumstances items. Three scales additionally correlated with the number of complex chronic condition diagnoses. This newly developed questionnaire can provide clinicians with first indications of possible sleep problems in a growing paediatric population.

KEYWORDS
chronic disease, palliative care, surveys and questionnaire

1 | INTRODUCTION

According to Feudtner and colleagues, paediatric complex chronic conditions (CCC) constitute "any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and involve either several different organ systems or one organ system severely enough to require specialty pediatric care and a period of hospitalization in a tertiary care center" (Feudtner et al., 2000, 2014). As a subpopulation of children with special healthcare needs (Carvalho et al., 2021), children with CCC represent a growing global population with diverse medical problems and increasing needs for intensive medical care (Arias López et al., 2020; Bjur et al., 2019).

To identify and classify children with CCC based on their ICD-10 diagnoses, an updated version of the CCC classification system (v2) was released in 2014 (Feudtner et al., 2014). CCC are classified into 10 main categories: cardiovascular, respiratory, neuromuscular, renal, gastrointestinal, haematological or immunological, metabolic, other congenital or genetic malignancy, and premature and neonatal (Feudtner et al., 2014).

Nevertheless, due to a wide range of different terminologies for children with complex needs, generalized prevalence rates for children with specific CCC are either unavailable or only sporadically available for local or national cohorts (Arias López et al., 2020; Bjur et al., 2019). It appears, however, that the number of patients with CCC has been increasing over the years (Bjur et al., 2019). CCC often occur cumulatively within one individual (Feudtner et al., 2021; Lindley et al., 2017); these patients are hospitalized more often, especially when multiple concurrent CCCs are present, with longer periods of intensive care time (Arias López et al., 2020; Burns et al., 2010; Lindley et al., 2017). This population also tends to suffer from a wide variety of symptoms of varying severity and distress (Feudtner et al., 2021; Marcus et al., 2021).

Sleep problems are a well-recognized problem in children with CCC with a prevalence ranging from about 50% to 70% (Hauer & Wolfe, 2014; Schwantes & O'Brien, 2014; Stangenes et al., 2017). For instance, the complex reciprocal relationship between epilepsy and substantial neuropsychological comorbidities (which include sleep problems) has been extensively researched (Beattie et al., 2016). Distressing symptoms such as sleep problems seem to particularly affect children with CCC who are approaching end-of-life (Marcus et al., 2021). This highlights the close link between CCC and children with life-limiting conditions and paediatric palliative care needs. Almost all children requiring paediatric palliative care suffer CCC, but not all CCC require a palliative care approach (Spicer et al., 2015).

Against this background, comprehensive and patient-centred diagnostics are an essential basis for effective therapy (Simard-Tremblay et al., 2011). Because implementing more objective methods is often costly and not feasible, proxy-completed sleep questionnaires offer a simple but effective way to obtain important indications for sleep problems (Kaleyias et al., 2012). At the same time, parents and caregivers are empowered to advocate for their child and actively participate in the care process (Bogetz et al., 2020).

Many of today's commonly employed sleep questionnaires, such as the Sleep Disturbance Scale for Children (SDCS; Bruni et al., 1996) and the Children's Sleep Habits Questionnaire (CSHQ; Owens et al., 2000), were originally developed for, and with, healthy children. The extent to which these questionnaires are reliable in children with substantial impairments, however, is unclear (Bautista et al., 2018). In 2013, the "Sleep Questionnaire for Children with Severe Psychomotor Impairment (SNAKE)" was the first questionnaire developed explicitly for children and adolescents with paediatric palliative care needs and psychomotor impairment (Blankenburg et al., 2013). In clinical practice and research, it has nevertheless been shown that the high population specificity of the SNAKE is disadvantageous when applied to children with CCC who do not suffer from life-limiting conditions or psychomotor impairment and who currently have no palliative care needs. Therefore, the aim of this study was to develop a sleep questionnaire for children with CCC that could be used for a wide range of patients.

2 | MATERIALS AND METHODS

2.1 | Participants

Study participants were recruited in three tertiary care paediatric hospitals in Germany from November 2020 to February 2022. Patients aged 1–25 years with a CCC (based on the classification by Feudtner et al., 2000, 2014) were eligible for the study. Children and adolescents with CCC often suffer from developmental (neurological) delays (Murphy, 2020); the upper age limit of this study was therefore extended to 25 years instead of 18 years to accommodate both a patient's developmental age and biological age, as is commonly postulated (Brand & Thorpe, 2016). Exclusion criteria were defined as insufficient parental language proficiency or the onset of an acute parental or patient crisis (e.g. acute loss of a close relative, serious illness).

For the pre-test, professionals at the lead institution (Children's and Adolescents' Hospital Datteln, Witten Herdecke University, Germany) were recruited. Professionals worked in medical, nursing or psycho-social fields. There were no inclusion or exclusion criteria.

Ethical approval was granted by the Ethics Committee of Witten/Herdecke University (approval code: 128/2020, approval date: 15 August 2020), the Ethics Committee of the Medical Department of Ludwig-Maximilians-University Munich (approval code: 20-0956, approval date: 3 December 2020) and the Ethics Committee of the Medical Association of Westphalia-Lippe (approval code: 2021-129-b-S, approval date: 9 March 2021). All families and professionals provided informed consent to participate in the study.

TABLE 1 Potential questionnaire items defined by the study expert team

No.	Item
	On how many of the last 7 days …
1	… did your child fall asleep too early?
2	… did your child fall asleep too late?
5	… did your child seem hyper during the day?
	On how many of the last 7 days did your child exhibit the following abnormalities of breathing during sleep?
6	Shallow breathing?
7	Drops in oxygen saturation (if the child is monitored with a saturation monitor)?
	On how many of the last 7 days did your child exhibit the following behaviours during sleep?
8	Head was hyperextended?
9	Made any other noticeable sounds?
10	Appeared to be in a state between wakefulness and sleep?
	On how many of the last 7 days did your child exhibit the following movements during sleep?
11	Muscle twitching?
	On how many of the last 7 days during the night was/were in your child's bedroom …
12	… sounds being made by other persons to be heard (e.g. conversations)?
	On how many of the last 7 days during the night/during daytime did your child experience …
13	… nausea/vomiting?
14	… constipation?
15	… wounds/decubiti?
16	… infections (e.g. flu-like infection)?

2.2 | Materials

The Sleep Screening for Children and Adolescents with Complex Chronic Conditions (SCAC) was developed after reviewing items from the SNAKE (Blankenburg et al., 2013) and other paediatric sleep questionnaires. Items were excluded from consideration if they did not reflect the basic diagnostic criteria of the main groups listed in the International Classification of Sleep Disorders (American Academy of Sleep, 2014), 3rd version (ICSD; insomnia, sleep-related breathing disorders, central disorders of hypersomnolence, circadian rhythm sleep–wake disorders, parasomnias, sleep-related movement disorders). These items reflect potential sleep-related abnormalities (scale items).

Items were screened by the study team whose members have expertise in CCC and paediatric palliative care. The expert team added two global items (How would you describe your child's overall sleep quality? Are you worried about your child's sleep?) and items relating to sleep circumstances (e.g. light, noise in the child's bedroom) to indicate possible causes for the sleep peculiarities. Items separate from the sleep questionnaires are defined in Table 1. Items regarding the child and family's demographic data were also added.

All potential items were worded for use in a German proxy assessment measure (assessment of a child/adolescent by parents). A proxy assessment was chosen because it can be completed independently of the child's developmental age and impairments (e.g. non-verbality). Children without the cognitive/linguistic abilities to answer the questions were excluded to maximize data comparability and to avoid needing to use parents as proxies for their child's responses, which would complicate the interpretation of our results. The expert team compiled the appropriate items into a single questionnaire for the pre-test version of the SCAC.

Parents and professionals rated each item's comprehensibility (*comprehensible*, *not comprehensible*) and relevance (*not relevant*, *somewhat relevant*, *quite relevant*, *very relevant*). The pre-test questionnaire queried a reference period of 7 days (e.g. "How often has your child during the last 7 days …?"). At the end of the pre-test questionnaire, its perceived length (*rather too short*, *appropriate*, *rather too long*, *much too long*), comprehensibility (*all questions are comprehensible*, *most questions are comprehensible*, *some questions are comprehensible*, *no question is comprehensible*) and relevance (*all questions are relevant*, *most questions are relevant*, *some questions are relevant*, *no question is relevant*) could be globally rated.

Based on the results of the pre-test, the potential scale items, global items, sleep circumstances items and demographic items were compiled into a questionnaire for the main test version of the SCAC. To maximize comprehensibility, each block of questions was preceded by a brief introduction.

All potential scale items were formulated to associate symptomatic behaviour with increasing response tendency (i.e. the more frequently a child exhibited a particular behaviour in the last 7 days, the more symptomatic they were). The final questionnaire was translated into English using forward–backward translation (Koller et al., 2012).

2.3 | Procedure

Between November 2020 and February 2021, the pre-test was conducted in the paediatric palliative care unit and neuropaediatric unit of the lead institution. On the paediatric palliative care unit, young patients with a broad spectrum of CCC diseases are cared for. This care is not primarily provided at the end of life, but rather over the course of the disease.

For this study, parents whose children were admitted as inpatients and had sufficient cognitive abilities were eligible to participate. Parents and staff members (professionals) were informed verbally and in writing about the study. Participating individuals were given the pre-test version of the SCAC.

For the main test, the SCAC was distributed to all participating facilities. Between June 2021 and February 2022, it was given to parents whose children presented either as inpatients or in the

corresponding ambulances. Further procedures were the same as the pre-test.

2.4 | Analysis

All analyses were performed using SPSS (IBM, version 28) and R (R Core Team, 2021) with RStudio.EE (R Studio Team, 2021).

For the pre-test, descriptive statistics describe the item ratings and demographics. Significant differences between the parent and professional responses were determined using a Mann–Whitney *U*-test. Items with significant clinical relevance and/or that had a mean comprehensibility of at least 90% and a relevance of at least "fairly/very relevant" were included in the main test. If item ratings fell below these defined limits, adjustments (e.g. adding examples) were applied to improve comprehensibility/relevance, and the study team reassessed them for inclusion.

For the main test, demographics were examined descriptively. Responses to items 2 ("How long did your child sleep, on average, during the night in total during the last 7 days?") and 6 ("How long has your child slept, on average, during the daytime in total during the last 7 days?") were grouped as "normal range/unremarkable", "too short sleep", "extremely too short sleep", "too long sleep" and "extremely too long sleep" using age-dependent norm values (Iglowstein et al., 2003; Data S1, Supplemental Material A).

A principal components analysis (PCA) was performed using data collected in the main test.

A PCA was chosen over confirmatory factor analysis because no comparable sleep instruments exist for children with CCC. Therefore, we did not formulate specific hypotheses regarding the resulting factor model. Furthermore, the proportion of total variance (rather than common variance) explained should be maximized. The resulting identified factors can be understood as "higher-level" constructs that summarize the variables, rather than as latent variables (like in Principal Axis Factoring). Unsystematically missing values (6.23%) were addressed using multiple imputation (predictive mean matching and $m = 20$) with the package "mice" (Van Buuren, 2018). We then calculated the variance–covariance matrix of all imputed datasets and pooled those into a single variance–covariance matrix, which in turn could be used in the PCA carried out with the "psych" package (Revelle & Revelle, 2017). Parallel analysis (Horn, 1965) determined the number of components to be extracted. The Kaiser–Meyer–Olkin Measure of Sampling Adequacy (Kaiser, 1974), required to be above a minimum of 0.60 (Tabachnick & Fidell, 2018), and Bartlett's Test of Sphericity (Bartlett, 1954) determined the data's suitability for PCA. Subsequently, a promax-rotated PCA (assuming intercorrelations) was conducted. Items with cross-loadings on more than one component were discarded to maintain a simple structure. Theoretically meaningful components with at least three pertinent loading coefficients were considered appropriate for inclusion. McDonald's ω measured the component's reliability (Hayes & Coutts, 2020; McDonald, 1999).

TABLE 2 Characteristics of professionals and parents who participated in the pre-test ($N = 60$)

Characteristics	
Professionals ($n = 35$)	
Age in years; M (SD)	38.88 (12.75)
Work experience in years; M (SD)	15.22 (11.24)
Profession; *n* (%)	
Nursing	23 (65.7)
Medicine	11 (31.4)
Psycho-social	1 (2.9)
Setting; *n* (%)	
Paediatric palliative care unit	21 (60)
Neuropaediatric unit	14 (40)
Scope of work; *n* (%)	
Full-time	24 (70.6)
Part-time	10 (29.4)
Parents ($n = 25$)	
Questionnaire completed by; *n* (%)	
Mother	20 (83.3)
Father	4 (16.7)
Mother's age in years; M (SD)	39.38 (9.19)
Father's age in years; M (SD)	42.30 (8.67)
Parental marital status; *n* (%)	
Married	12 (57.1)
Not married	4 (19.1)
Separated/divorced	5 (23.8)

Item-level analysis included mean, response range, difficulty and discriminability. For item difficulty, items with a score of < 0.20 were interpreted as *very difficult*, 0.50 as *intermediate*, and > 0.80 as *very easy* (Gulliksen, 1945). The following conventions were used to interpret item discriminatory power: < 0.19 as *poor*, 0.20–0.29 as *marginal*, 0.30–0.39 as *good*, ≥ 0.40 as *very good* (Ebel & Frisbie, 1972).

For preliminary validation, the identified factors' scale values were determined by calculating mean indices. Subsequently, these were correlated with each other, with the two global items, sleep circumstances items, the number of CCC diagnoses, and the care level of the included children and adolescents. In Germany, the latter indicates the degree to which a patient requires care, ranging from 1 (slight impairment of independence) to 5 (most severe impairment of independence with special requirements for nursing care). For all of these variables it was hypothesized that higher scale values (implying increasingly conspicuous sleep behaviour) should also be associated with greater impairment for the other variables (e.g. greater parental concern, presence of multiple CCC diagnoses). Regression analyses were used to detect possible age and gender effects on the SCAC scale values. Multiple comparisons were adjusted via false discovery rate correction (Pike, 2011).

3 | RESULTS

3.1 | Pre-test

A total of $N = 60$ individuals ($n = 35$ professionals, $n = 25$ family caregivers of children with CCC) rated the pre-test questionnaire covering 78 sleep-specific and 20 demographic items. Participants' characteristics are shown in Table 2.

No item had to be excluded due to insufficient comprehensibility; all average ratings were > 90%. Nevertheless, based on participant feedback, a new item was introduced to further improve other items' comprehensibility: "How often did your child wake up, on average, per night in total during the last 7 days?". Ten items were below the defined limit of "fairly/very relevant", so their wording was modified to potentially increase relevance (Table 3).

Regarding the global evaluation of the pre-test questionnaire, most respondents indicated that it was of adequate length, that all

TABLE 3 Initial and adjusted wording of pre-test items rated below the defined relevance threshold

Intended allocation	Relevance score	Initial wording	Adjusted wording[a]
Scales	2.65	… did your child fall asleep too early?	… did your child fall asleep too early **(more than 1 hr before the desired time)**?
Scales	2.88	… did your child fall asleep too late?	… did your child fall asleep too late **(more than 1 hr after the desired time)**?
Scales	2.84	… did your child wake up too early in the morning?	… did your child wake up too early in the morning **(more than 1 hr before the desired time)**?
Scales	2.94	Head hyperextended?	Head was hyperextended **backwards**?
Scales	2.80	Vivid dreaming?	Vivid dreaming?
Scales	2.85	Moaning?	Moaning?
Scales	2.90	Made any other noticeable sounds?	Made any other noticeable sounds **(e.g. whistling, laughing up)**?
Scales	2.98	Appeared to be in a state between wakefulness and sleep?	Appeared to be in a state between wakefulness and sleep?
Scales	2.88	Punched or kicked around?	Punched or kicked around?
Sleep circumstances	2.86	… the door open?	… the door open?

[a]Changes are shown in bold.

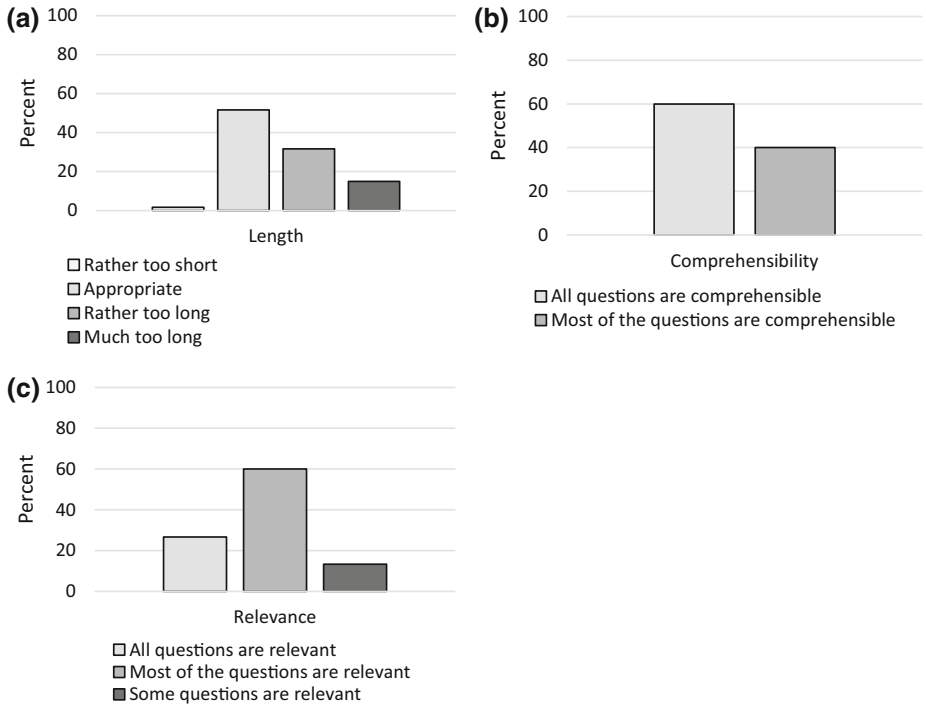

FIGURE 1 Participants' global assessments of the pre-test questionnaire's length, comprehensibility and relevance

TABLE 4 Characteristics of children and adolescents in the main test sample ($N = 315$)

Characteristics	
Age in years; *M* (*SD*)	9.58 (5.61)
Sex; *n* (%)	
Female	149 (47.3)
Male	166 (52.7)
Born premature; *n* (%)	
No	239 (78.4)
Yes	66 (21.6)
Care level; *n* (%)[a]	
None	134 (44.1)
1	12 (3.9)
2	24 (7.9)
3	31 (10.2)
4	42 (13.8)
5	61 (20.1)
Diagnoses	
Number of different CCC; *n* (%)	
1	212 (67.3)
2	62 (19.7)
3	28 (8.9)
4	12 (3.8)
5	1 (0.3)
Presence of diagnostic main groups; *n* (%)[b]	
Examples of diseases seen in participants	
Neurological and Neuromuscular	281 (89.2)
Epilepsy, Infantile Cerebral Palsy, Agenesis of the Corpus Callosum	
Other Congenital or Genetic Defect	43 (13.7)
Chromosomal anomalies, Mowat-Wilson Syndrome	
Premature and Neonatal	30 (9.5)
Cerebral Leukomalacia, Hypoxic–Ischaemic Encephalopathy	
Malignancy	7 (2.2)
Infantile ganglioglioma, Neurofibromatosis	
Metabolic	6 (1.9)
X-Linked Adrenoleukodystrophy, Glut-1 deficiency syndrome	
Cardiovascular	3 (0.9)
Long QT syndrome, dilated cardiomyopathy	
Haematological or Immunological	2 (0.6)
Severe immune thrombocytopaenia, ATRX syndrome	

[a]In Germany, the care level expresses the degree to which a patient requires care ranging from 1 (slight impairment of independence) to 5 (most severe impairment of independence with special requirements for nursing care).
[b]According to the CCC classification system version 2 (Feudtner et al., 2014); multiple diagnoses/entries possible.
Abbreviation: CCC, complex chronic conditions.

questions were understandable, and that most of the questions were relevant (Figure 1). There was no significant difference between parent and professional assessments (all $p > 0.05$).

3.2 | Main test

Data for $N = 315$ children and adolescents with CCC were included in the PCA (Table 4).

The Kaiser–Meyer–Olkin Measure of Sampling Adequacy (Kaiser, 1974) was 0.81, considerably exceeding the minimum standard for performing a PCA. Further, the Bartlett's Test of Sphericity (Bartlett, 1954) showed that the correlation matrix was not an identity matrix, $\chi^2(820) = 4979.60$, $p < 0.001$. Consequently, it was ascertained that the correlation matrix was suitable for PCA.

The results of the parallel analysis (Horn, 1965) and scree (Cattell, 1966) clearly revealed that a four-component solution best represented the data. The study team determined the following four factors: "Falling and staying asleep" (loaded by seven items), "Sleep-associated respiration and arousal" (loaded by nine items), "Daytime sleepiness" (loaded by seven items) and "Sleep-associated movements" (loaded by six items; Table 5). Due to coefficients with a factor loading lower than the defined threshold of 0.40, a total of 11 analysed items were dropped for the final component structure (Data S2, Supplemental Material B). No coefficients were discarded due to cross-charges above 0.40. The components' reliabilities were acceptable, ranging from 0.63 to 0.84 (Taber, 2018; van Griethuijsen et al., 2015; Table 5).

Item-level analysis showed that item difficulty was mostly *high* to *very high* with rather low item mean values; all items possessed a discriminatory power that could be classified as *very good* (Table 5). For all items, participants used the full 0–7-day response range.

Within the scope of the preliminary validation, mean scale values ranged from 0.49 (Sleep-associated movements, $SD = 1.07$) to 2.42 (Falling and staying asleep, $SD = 1.49$; Sleep-associated respiration and arousal: $M = 1.10$, $SD = 1.25$; Daytime sleepiness: $M = 1.28$, $SD = 1.20$) in the overall group of children with CCC. Regarding the specific types of CCC, children with cardiovascular diseases scored highest on average on the "Daytime sleepiness" scale, children with metabolic diseases scored highest on the "Falling and staying asleep" scale, children with Other Congenital or Genetic Defects scored highest on the "Sleep-associated movements" scale, and those with Premature and Neonatal diseases scored highest on the "Sleep-associated respiration and arousal" scale (Figure 2).

All four scales were positively and significantly correlated with the two SCAC global items and a child's care level. Except for the scale "Falling and staying asleep", three scales were positively correlated with a child's number of CCC diagnoses. All four scales also correlated positively with a varying number of the 28 children's sleep circumstance items (range: correlation with 8–25 of 28 items; Table 6). Scale values of female and male patients did not differ (all $p > 0.05$). Lower "Falling and staying asleep" values were associated with increasing age ($R^2 = -0.07 \pm 0.01$, $p < 0.001$). The final English version of the SCAC (completion time approximately 15–20 min) can be found in Data S3, Supplemental Material C.

TABLE 5 Item analysis results and factor loadings based on the PCA with $N = 315$ participants[a]

	Item analysis			Components 1–4			
Items	Mean	Difficulty[b]	Discriminability[c]	Falling and staying asleep	Sleep-associated respiration and arousal	Daytime sleepiness	Sleep-associated movements
On how many of the last 7 days …							
… did it take more than 20 min until your child fell asleep?	3.41	0.48	0.64	0.63			
… did your child fall asleep too late (more than 1 hr after the desired time)?	2.09	0.29	0.62	0.57			
… did your child need support from you or another person to fall asleep (e.g. falling asleep together in one bed, rocking, holding hands, singing)?	2.35	0.33	0.55	0.68			
… did your child need support from anything else to fall asleep (e.g. nightlight, cuddly toy, radio)?	3.85	0.55	0.48	0.44			
… did your child wake up by itself (without any recognizable "disturbing influences") during the night?	2.08	0.29	0.58	0.54			
… did your child seem irritable during the day?	1.80	0.25	0.61	0.54			
… did your child seem hyper during the day?	1.35	0.19	0.55	0.55			
On how many of the last 7 days did your child exhibit the following abnormalities of breathing during sleep?							
Snored?	1.59	0.22	0.65		0.69		
Slept with mouth open?	2.99	0.42	0.59		0.48		
Strained breathing?	0.88	0.12	0.72		0.70		
Shallow breathing?	1.30	0.18	0.63		0.53		
Breathing stops?	0.33	0.04	0.69		0.74		
Drops in oxygen saturation (if the child is monitored with a saturation monitor)?	0.47	0.06	0.75		0.83		
Woke up with shortness of breath?	0.10	0.01	0.43		0.41		
On how many of the last 7 days did your child exhibit the following behaviours during sleep?							
Head was hyperextended backwards?	0.92	0.13	0.58		0.56		
Muscle twitching?	1.14	0.16	0.55		0.45		
Appeared to be in a state between wakefulness and sleep?	0.72	0.10	0.63			0.47	
On how many of the last 7 days …							
… did your child seem tired during the day?	2.90	0.41	0.73			0.71	
… did your child seem limp during the day?	2.14	0.30	0.78			0.78	
… did your child have a strong urge to sleep during the day that was hard to suppress?	1.23	0.17	0.75			0.83	
… did your child sleep unplanned during the day (e.g. suddenly falling asleep)?	0.90	0.12	0.71			0.81	
… did your child fall asleep too early (more than 1 hr before the desired time)?	0.63	0.09	0.56			0.50	
How long has your child slept, on average, during the daytime in total during the last 7 days? - grouped; too long	0.45	0.22	0.56			0.67	
On how many of the last 7 days did your child exhibit the following movements during sleep?							
Movements that disturbed her/his sleep or falling asleep?	0.71	0.10	0.60				0.42
Flailed or kicked?	0.33	0.04	0.54				0.42
Repeated, rhythmic movements of the arms?	0.56	0.08	0.83				0.89
Repeated, rhythmic movements of the legs?	0.65	0.09	0.78				0.82

(Continues)

TABLE 5 (Continued)

Items	Item analysis			Components 1–4			
	Mean	Difficulty[b]	Discriminability[c]	Falling and staying asleep	Sleep-associated respiration and arousal	Daytime sleepiness	Sleep-associated movements
Repeated, rhythmic movements of other body parts (e.g. trunk, head)?	0.45	0.06	0.77				0.83
Any other noticeable movements (e.g. swinging of the head)?	0.48	0.06	0.61				0.53
Reliability				0.63	0.79	0.84	0.80

[a]Discarded items with insufficient factor loadings (< 0.40) are not displayed in this table.
[b]Desirable: about 0.50 (intermediate).
[c]Desirable: > 0.39 (good).

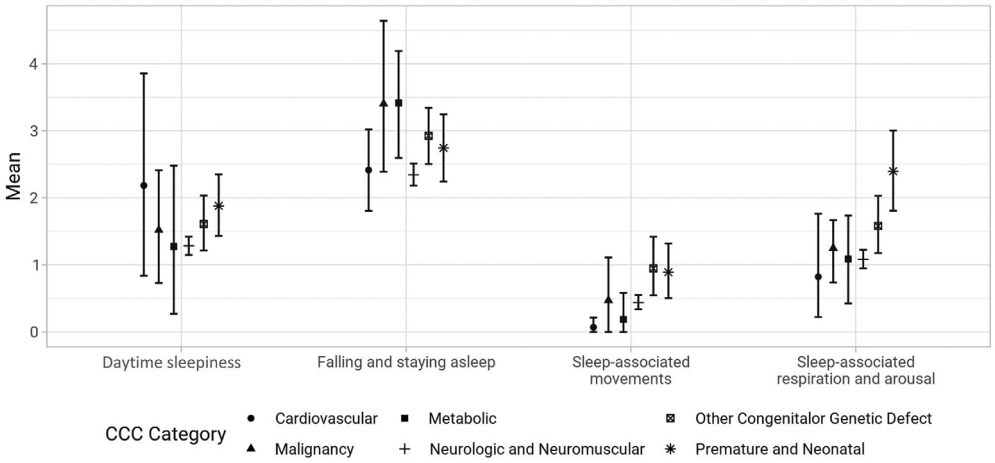

FIGURE 2 Mean Sleep Screening for Children and Adolescents with Complex Chronic Conditions (SCAC) scale scores (with 95% confidence intervals) of children with different underlying conditions grouped according to the Complex Chronic Conditions (CCC) classification system (Feudtner et al., 2014)

4 | DISCUSSION

Due to their increasing prevalence and medical complexity, children and adolescents with CCC are a priority for health systems optimization (Arias López et al., 2020; Berry et al., 2015; Bjur et al., 2019). With the development of the SCAC, the present study supplements and optimizes the diagnosis of a common symptom in this population (Schwantes & O'Brien, 2014).

Based on a thorough literature research and expert knowledge, four clinically relevant components of common sleep problems in children and adolescents were identified: "Falling and staying asleep", "Sleep-associated respiration and arousal", "Daytime sleepiness", and "Sleep-associated movements".

The reliability of the four components was "acceptable to good" according to common conventions. While higher reliabilities are desirable, high internal consistency is more likely to occur in homogeneous than heterogeneous samples (Streiner, 2003). The examined children and adolescents with CCC are a highly heterogeneous sample with different numbers of diagnoses, illness severity, disorder complexity and developmental ages (Berry et al., 2015). Therefore, the reliabilities we identified are satisfactory.

The questionnaire also showed adequate psychometric properties. In particular, the selected items seem to be very well suited for distinguishing problematic from unproblematic sleep behaviour. A rather high item difficulty is reasonable, as the questionnaire had to be primarily designed in such a way that it was capable of reflecting and accommodating the special features of children and adolescents who are heavily affected by CCC and sleep problems. In the total population of children and adolescents with CCC and in our sample, however, these severely impaired children and adolescents affected by sleep problems seem to make up a smaller proportion than those who have CCC but are only restricted by it in certain functional areas and to a lesser extent. For the latter subgroup, many items might therefore be more difficult, as the described behaviours are rather less frequent in them (e.g. awakening with respiratory distress). Because our questionnaire is a screening tool applicable to the wide range of diverse CCC, this parameter is satisfactory.

Nearly all scales correlated with one or more of the other variables investigated. The correlation of all scales with the two global items and the child's care level support the scales' validity. As expected, higher scale scores are also associated with a child's worsening sleep quality, impairment and parental concern about the child's sleep.

TABLE 6 Correlations of scale means with global items, care level, number of CCC diagnoses and sleep circumstances[a]

	Scales 1–4							
	Falling and staying asleep		Sleep-associated respiration and arousal		Daytime sleepiness		Sleep-associated movements	
Items	*r*	*p*	*r*	*p*	*r*	*p*	*r*	*p*
Scales 1–4								
Falling and staying asleep			0.40		0.38		0.22	
Sleep-associated respiration and arousal	0.40				0.48		0.35	
Daytime sleepiness	0.38		0.48				0.47	
Sleep-associated movements	0.22		0.35		0.47			
Global items								
How would you describe your child's overall sleep quality?	0.45	< 0.001	0.47	< 0.001	0.47	< 0.001	0.32	< 0.001
Are you worried about your child's sleep?	0.36	< 0.001	0.46	< 0.001	0.41	< 0.001	0.38	< 0.001
Care level	0.16	0.007	0.47	< 0.001	0.29	< 0.001	0.26	< 0.001
Number of CCC diagnoses			0.41	< 0.001	0.26	< 0.001	0.14	0.01
Sleep circumstances								
On how many of the last 7 days during the night was/were in your child's bedroom …								
… a light (e.g. ceiling light, night light) switched on?	0.20	< 0.001	0.13	0.038				
… environmental noises to be heard (e.g. street noise, monitor noise?)			0.23	< 0.001	0.12	0.046		
… sounds being made by other persons to be heard (e.g. conversations)?					0.17	0.003		
… an electronic entertainment device switched on (e.g. Toni Box, TV, radio, tablet, computer)?	0.14	0.017	0.17	0.006	0.18	0.002		
… the door opened?	0.14	0.025						
On how many days of the last 7 days …								
… was your child repositioned at night?			0.55	< 0.001	0.26	< 0.001	0.23	< 0.001
… was your child provided with assistive devices at night (e.g. orthoses)?			0.13	0.028				
… was your child ventilated at night?								
… was your child suctioned at night?			0.19	< 0.001	0.20	< 0.001		
… was your child nappy changed at night?			0.38	< 0.001	0.26	< 0.001	0.15	0.015
… was your child given food or fluids at night?	0.15	0.014	0.47	< 0.001	0.36	< 0.001	0.19	0.002
… was your child given medication/infusions at night?			0.43	< 0.001	0.26	< 0.001	0.12	0.046
On how many of the last 7 days during the night did your child experience …								
… pain?			0.50	< 0.001	0.36	< 0.001	0.28	< 0.001
… irritability?	0.38	< 0.001	0.43	< 0.001	0.39	< 0.001	0.40	< 0.001
… seizures?			0.38	< 0.001	0.26	< 0.001	0.19	< 0.001
… severe spasticity?			0.34	< 0.001	0.24	< 0.001	0.29	< 0.001
… nausea/vomiting?			0.39	< 0.001	0.33	< 0.001		
… constipation?	0.13	0.037	0.42	< 0.001	0.32	< 0.001	0.30	< 0.001
… wounds/decubiti?			0.32	< 0.001	0.20	< 0.001	0.44	< 0.001
… infections (e.g. flu-like infection)?			0.24	< 0.001				
On how many of the last 7 days during the daytime did your child experience …								
… pain?			0.38	< 0.001	0.28	< 0.001		
… irritability?	0.37	< 0.001	0.41		0.32	< 0.001	0.36	< 0.001
… seizures?			0.27		0.25	< 0.001	0.19	0.002
… severe spasticity?			0.34		0.20	< 0.001	0.29	< 0.001

(Continues)

TABLE 6 (Continued)

	Scales 1–4							
	Falling and staying asleep		Sleep-associated respiration and arousal		Daytime sleepiness		Sleep-associated movements	
Items	*r*	*p*	*r*	*p*	*r*	*p*	*r*	*p*
… nausea/vomiting?			0.45		0.36	< 0.001	0.16	0.008
… constipation?	0.13	0.032	0.33		0.29	< 0.001	0.34	< 0.001
… wounds/decubiti?			0.28		0.14	0.019	0.38	< 0.001
… infections (e.g. flu-like infection)?			0.20					

[a]Only significant correlations are depicted in the table.
Abbreviation: CCC, complex chronic conditions.

Many of the children and adolescents in the study suffered from more than one CCC, which is consistent with the existing literature describing the often cumulative nature of CCC (Burns et al., 2010; Feudtner et al., 2014; Hardelid et al., 2014). At the same time, this speaks to the high generalizability of our results and the applicability of the SCAC to children and adolescents with CCC. The most common CCC diagnoses in this study were classified as "Neurological and Neuromuscular" (Feudtner et al., 2014). While this is one of the most prevalent groups, children and adolescents who die of CCC are frequently affected by neurological and neuromuscular diseases (Feudtner et al., 2021; Hardelid et al., 2014). This is plausible, as our study also included children with life-limiting illnesses and paediatric palliative care needs; a subpopulation that frequently suffers from neurological diseases (Fraser et al., 2020).

We expected that the scales would be positively associated with the number of CCC diagnoses, as sleep problems may increase with the accumulation of different diagnoses (Feudtner et al., 2021; Lindley et al., 2017). Validation analyses confirmed this association for three of the four scales; why the "Falling and staying asleep" scale did not correlate with number of diagnoses cannot be assessed within the scope of this study. It is possible that problems falling asleep and staying asleep are influenced less by the number—and more by the specific type and severity—of CCC diagnoses. Follow-up studies should aim to better explain this phenomenon.

All four scales correlated with a different number of sleep circumstances variables, supporting their validity. This result further highlights the clinical relevance of sleep circumstances. Including these items in the questionnaire can help improve understanding of children's sleep problems and identify possible conditioning factors.

The results show that the SCAC helps in screening for which sleep problems occur (more frequently) in the individual CCC categories. Information such as this can contribute to the availability of specific diagnostic and therapeutic options for children with different underlying diseases in the corresponding care facilities and thus to be able to act in a forward-looking, economical and patient-centred manner.

In this study, younger children in particular seemed to have more frequent problems falling asleep and staying asleep. Although this observation has been reported in the literature, the statistical effect here was small. After a comprehensive validation of the SCAC, follow-up studies with larger sample sizes should evaluate whether this effect can be replicated and whether there are age effects regarding the other three scales. This would be important information for clinical practice, in that treatment programmes for patients with complex chronic diseases could be designed for specific age groups. Even though we followed the ICSD criteria in defining the items of the questionnaire, the "disorder character" (e.g. in the sense of "falling and staying asleep disorders") was deliberately omitted in the naming of the final scales. This was primarily due to our results, which showed that the scales were not exactly composed of the items that represent the individual diagnostic criteria of a disorder in the ICSD. This fact is possibly due to a large potential intersection of the different sleep disorder characteristics. More specifically, the ICSD suggests that different sleep problems and sleep disorders share similar or even the same characteristics, and thus are never completely separable from each other (American Academy of Sleep, 2014). Whereas movement disorders, for example, can be described very homogeneously by a narrowly defined behavioural repertoire, disorders of falling asleep and staying asleep are key features of insomnia, but can also manifest themselves, for example, in the context of breathing problems or sleep–wake rhythm disorders (American Academy of Sleep, 2014). This consideration is also supported by the finding that the SCAC scales correlate with each other. These correlations also support our decision to perform a promax-rotated PCA.

At the same time, sleep questionnaires in general have limitations. Although they can provide initial, rough indications of possible sleep problems, further diagnostic measures are required for precise differentiation and clinical diagnosis. This circumstance is also indicated in the ICSD (e.g. performance of a polysomnography if respiratory disorders are suspected; American Academy of Sleep, 2014). Therefore, the present questionnaire does not aim to be an exclusive diagnostic measure for children and adolescents with CCC, but rather a screening tool to help clinicians quickly and easily identify necessary diagnostic and/or therapeutic action.

4.1 | Limitations

Despite our preliminary validation of the SCAC with promising results, further research is warranted to validate its use in children and adolescents with CCC. The SCAC is currently only available in German and English. In the future, it should be systematically translated into other languages (e.g. forward–backward translation; Degroot et al., 1994). Families of differing ethnic backgrounds should also be surveyed. Preferably, validation of the other language measures should be provided.

Following the established rule of thumb that factor analyses should be performed with 10 respondents per considered variable, our sample size of 315 patients is less than the desired 410 patients. Nonetheless, there is ongoing discussion that appropriate metrics for determining the ideal sample size of a factor analysis are heterogeneous and subject to numerous parameters. Also, there is evidence that valid results can be generated from even smaller samples (McNeish, 2017). Following Mundfrom et al. (2005), however, our study's sample size exceeds the minimum 110–180 subjects required for describing a four-factor solution.

The SCAC was not compared with a "gold-standard" such as polysomnography or a clinical interview in this study. Consequently, no conclusions can be drawn regarding the sensitivity or specificity of the instrument; cut-off values for deciding whether SCAC results are clinically meaningful (clinically significant thresholds indicating the need for therapeutic action) are missing. However, the primary objective of this preliminary study was to validate whether the questionnaire can assess sleep problems in children with CCC so that this limitation is entirely justifiable at the present development stage. The identification of clinically meaningful cut-off values based on a gold-standard measure of sleeping problems should nevertheless be a priority of a future validation study. In this context, the extent to which the SCAC is consistent with other sleep diagnostic measures should also be examined in terms of congruent validity.

5 | CONCLUSIONS

We developed a screening questionnaire that can identify potential sleep peculiarities in children and adolescents with CCC. The instrument uses information provided by parents to quickly and easily flag potential sleep problems and whether further diagnostic measures are needed. In contrast to the SNAKE sleep questionnaire, the SCAC can screen sleep problems not only in critically ill children with, for example, life-limiting conditions, but also larger target populations. It has high potential for application in clinical practice. The SCAC is not limited to paediatric clinics. It can also be used in outpatient settings, corresponding care facilities (e.g. nursing services, paediatricians and specialists in private practice), all of which can benefit from this questionnaire's straightforward and reliable screening to provide young patients with fast, tailored and high-quality care. An ongoing validation of the SCAC will provide further important information regarding its quality and applicability.

AUTHOR CONTRIBUTIONS

Study design: Larissa Alice Kubek, Boris Zernikow, Julia Wager. *Data acquisition*: Larissa Alice Kubek, Kevin Rostasy, Annikki Bertolini, Mareike Schimmel, Georg Classen. *Data analysis*: Larissa Alice Kubek, Benedikt Claus. *Written article*: Larissa Alice Kubek. *Article revisions*: Benedikt Claus, Kevin Rostasy, Annikki Bertolini, Mareike Schimmel, Michael C Frühwald, Georg Classen, Boris Zernikow, Julia Wager. *Approval of final manuscript*: Larissa Alice Kubek, Benedikt Claus, Kevin Rostasy, Annikki Bertolini, Mareike Schimmel, Michael C Frühwald, Georg Classen, Boris Zernikow, Julia Wager.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Anonymized data are available from the corresponding author upon reasonable request.

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