

“Commentary on the Post-Print of ‘International Consensus on Sleep Problems in Pediatric Palliative Care: Paving the Way’ ”

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Abstract

In the field of pediatric palliative care (PPC), sleep problems, although among the most common symptom burdens, have not been adequately addressed due to insufficient attention. At present, the lack of relevant clinical guidelines and standards urgently needs to be resolved in order to fill the gap in the management of sleep problems in this field. Against this background, an international group of experts in pediatric sleep and palliative care developed the world’s first document entitled “International consensus on sleep problems in pediatric palliative care: Paving the way,” which was published in *Sleep Medicine* in July 2024. Based on a systematic review and meta-analysis of relevant studies, this consensus focuses on three major themes—definition, assessment/measurement, and treatment of sleep problems in PPC—and, following two rounds of Delphi surveys summarizing these themes, synthesizes a total of 53 consensus recommendations. However, this consensus still has limitations in terms of covering all heterogeneous pediatric patient groups and its applicability in low- and middle-income countries. This article interprets all the established consensus statements and offers recommendations, with the aim of providing a reference for the future development of localized, evidence-based guidelines in China and enhancing the standardization of sleep problem management within Chinese PPC.

Full Text

Interpretation of International Consensus on Sleep Problems in Pediatric Palliative Care: Paving the Way

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Abstract

Sleep disturbances, as a prevalent symptom burden in pediatric palliative care (PPC), remain inadequately addressed due to insufficient clinical attention. The current lack of standardized clinical guidelines and protocols urgently demands resolution to bridge the gap in sleep-related symptom management within this field. In response, the International Expert Panel on Pediatric Sleep and Palliative Care developed the inaugural global consensus, "International Consensus on Sleep Disturbances in Pediatric Palliative Care: Paving the Way," published in *Sleep Medicine* in July 2024. This consensus employed systematic reviews and meta-analyses of existing evidence, focusing on three core themes: definition, assessment/measurement, and therapeutic interventions for sleep disturbances in PPC. Through a two-round Delphi process, 53 consensus recommendations were formulated. However, limitations persist regarding the applicability of these recommendations across heterogeneous pediatric populations and in low- and middle-income countries. This article provides a critical interpretation and suggestions for the consensus, aiming to inform the development of evidence-based, culturally adapted guidelines in China and enhance the standardization of sleep disturbance management within Chinese PPC practice.

Keywords: Palliative care; Pediatric palliative care; Sleep problems; Expert consensus; Interpretation

1 Background of Consensus Interpretation

Pediatric palliative care (PPC) aims to improve quality of life for children with life-limiting illnesses, yet sleep problems—one of the most common symptom burdens—have long been underestimated in clinical practice [1]. Research indicates that 50%–80% of PPC patients suffer from sleep disorders, manifesting as insomnia, circadian rhythm disturbances, and nocturnal awakenings, which severely compromise immune function, emotional stability, and disease coping capacity, potentially accelerating disease progression. However, existing general pediatric sleep management recommendations inadequately address the multi-dimensional challenges in PPC, including disease heterogeneity (e.g., oncology, neurodegenerative disorders), treatment side effects (e.g., opioid-induced respiratory depression), and end-of-life stage-specific needs (e.g., environmental adaptation difficulties), resulting in a lack of standardized clinical guidance [3]. Systematic research on sleep problems in Chinese PPC remains scarce, with clinical interventions still largely reliant on empirical practices and lacking unified standardized protocols, creating a gap with the comprehensive care philosophy emphasized in “child-friendly hospital” initiatives.

In this context, the *International Consensus on Sleep Problems in Pediatric Palliative Care: Paving the Way* [4] (hereafter “the Consensus”) represents the first specialized document globally dedicated to sleep management in PPC, offering valuable reference points for Chinese clinical practice. Developed by the Pediatric Sleep and Palliative Care Group, the Consensus was based on systematic reviews and involved 72 interdisciplinary experts from 18 countries through a two-round Delphi process. Covering three major themes—definition, assessment, and treatment—the Consensus provides crucial scientific evidence to fill international practice gaps and promote the development of localized guidelines in China. This interpretation follows the *Guidelines for Reporting Guideline Interpretation Literature (RIGHT for INT)* [5] and was completed by a multidisciplinary clinical team in collaboration with evidence-based medicine specialists. The author team possesses both PPC clinical experience and guideline methodology expertise, with no conflicts of interest related to the Consensus, ensuring objectivity and professionalism. The target audience includes three groups: (1) frontline PPC clinicians (physicians and nurses in general pediatrics and palliative care units) seeking practical guidance on assessment tool selection and intervention planning; (2) multidisciplinary team (MDT) members (sleep medicine specialists, child psychologists, rehabilitation therapists) requiring clarity on collaborative roles; and (3) policymakers and guideline researchers who need evidence-based support for local guideline development and resource allocation, as well as educators in pediatric nursing and palliative care programs.

2 Background of Consensus Development

The Consensus was led by the International Pediatric Sleep and Palliative Care Expert Group and published in *Sleep Medicine* in July 2024. The target population includes children with life-limiting illnesses (encompassing oncology, genetic/metabolic disorders, severe neuromuscular diseases) and their caregivers, applicable across diverse settings including hospital palliative units, home hospice care, and primary healthcare facilities.

Given the significant disease heterogeneity in PPC (e.g., differing mechanisms between chemotherapy-related insomnia in cancer and circadian rhythm disturbances in neurodegenerative disorders), existing general pediatric guidelines lack targeted solutions. Global research remains fragmented, typically confined to single symptoms or specific populations without systematic analysis. Moreover, sleep management in clinical practice involves multiple components such as pain control and psychological support, yet professional barriers hinder effective interdisciplinary integration [6]. The Consensus addresses these gaps by establishing a standardized framework for PPC sleep management and providing a methodological paradigm for future research through multinational collaboration. The development process received no dedicated funding, and all participants served without remuneration. All members completed conflict-of-interest declarations, with those having conflicts excluded, ensuring no conflicts of interest among current participants.

3 Consensus Development Methods

The Consensus was developed using an evidence-based approach combining systematic reviews, meta-analyses, and a modified Delphi method. A steering committee of 10 authoritative experts systematically searched databases including PubMed and the Cochrane Library, focusing on three core themes: definition, assessment, and treatment of sleep problems. Seventy-two interdisciplinary experts from 18 countries with over five years of clinical experience were selected for the Delphi panel, serving as both core contributors and blinded voters.

The first round employed a 5-point Likert scale for 61 statements (consensus threshold $\geq 75\%$ expert agreement) criterion was used uniformly without further classification into “strong” or “weak” recommendations, aligning with the high disease heterogeneity and complex clinical scenarios in PPC. This approach avoids clinical ambiguity from recommendation grading while enhancing transparency and traceability through expert qualification review, blind voting, and high response rates, thereby improving credibility.

4 Interpretation and Recommendations

This section interprets the 53 consensus recommendations to enhance standardized sleep management in Chinese PPC and inform future development of localized evidence-based guidelines.

4.1.1 Multifactorial Pathogenesis and Comorbidity Characteristics of Sleep Problems in PPC

Based on high-consistency evidence (99% for multifactorial pathogenesis, 90% for comorbidity features), the Consensus clarifies that PPC sleep problems arise from multidimensional interactions among physiological factors (disease symptoms, treatment side effects), psychological factors (anxiety), and environmental factors (ward noise/light, medical disruptions), often forming “comorbid sleep disorder clusters.” For example, pediatric oncology patients may concurrently experience chemotherapy-related insomnia and opioid-induced respiratory depression, with comorbidities significantly worsening fatigue and quality-of-life impairment [7].

In Chinese clinical practice, only approximately 12% of primary hospitals achieve universal pain assessment for all outpatients and inpatients, while about 60% of departments perform no routine pain assessment, relying primarily on subjective complaints for dynamic monitoring [8]. Meanwhile, less than 30% of medical institutions are equipped with child-specific psychological assessment tools, with many still using simplified adult scales. Regarding hospital environment, noise, lighting, and irregular nursing workflows are confirmed as major sleep disruptors, with nighttime noise frequently exceeding 60 dB and lighting levels difficult to control at appropriate nighttime levels, significantly impairing sleep quality [9].

Therefore, for Chinese PPC patients, we recommend constructing a three-dimensional assessment system integrating physiological, psychological, and environmental dimensions, combining pain behavior observation scales, child anxiety screening tools, and ward noise/light monitoring records to identify comorbidities. For interventions, individualized protocols should be developed: environmental optimization can employ low-cost measures such as providing earplugs and installing adjustable dim lighting, while multidisciplinary collaboration can involve sleep specialists through remote consultation [10]. These recommendations differ from current single-symptom assessment and absent environmental intervention practices, constructing a management pathway across assessment dimensions, intervention measures, and resource integration to achieve precise sleep management adapted to Chinese healthcare resource conditions.

4.1.2 Core Impact of Pain on Sleep Disturbances and Unresolved Areas Regarding Underlying Diseases and Concomitant Medications

Based on 95% consensus evidence, the Consensus identifies pain as the core driver of sleep disturbances in PPC. Among children with advanced cancer, 75% experience pain, with over 50% of sleep disturbances directly caused by pain. The two conditions form a vicious cycle: sleep disturbances disrupt endogenous opioid systems, increasing pain sensitivity and exacerbating functional impairment and quality-of-life decline [11-12]. The Consensus also notes that the impact of primary underlying diseases and concomitant medications on sleep remains unresolved, constrained by disease heterogeneity, pediatric research ethics limitations, and insufficient outcome timeliness [13].

In Chinese clinical practice, collaborative assessment of pain and sleep suffers from single-dimension evaluation and insufficient dynamic monitoring frequency. Assessment of sleep impacts from underlying diseases and medications has not yet established a full-process standardized pathway covering disease progression, medication monitoring, and sleep feedback [14]. Additionally, pediatric sleep specialist resources are relatively insufficient to meet the needs of comprehensive precision management.

The Consensus offers valuable guidance for Chinese clinicians to: (1) establish a collaborative system integrating quantitative pain assessment and multidimensional sleep evaluation with regular dynamic monitoring to capture association changes; (2) develop a comprehensive assessment chain combining disease stage documentation, medication use logs, and parent-assisted sleep logs to support clinical decision-making in unresolved areas; and (3) conduct reassessment 1-2 weeks after pain intervention adjustments or medication changes. Through multidisciplinary collaboration and multi-center technical outreach, these strategies enhance professional support capacity and ensure deep alignment between consensus guidance and actual needs in Chinese PPC sleep management.

4.1.3 Unresolved Issues on Sedation-Medication Interactions and Anxiety/Fear-Induced Insomnia

The Consensus identifies two unresolved issues in PPC sleep management: (1) the relationship between sedation, medication interactions, and analgesic effects, as immature drug-metabolizing enzymes and significant individual variability in children, combined with difficult pain assessment, make it challenging to distinguish whether sedation originates from pain relief, drug characteristics, or polypharmacy synergy [15]; and (2) whether anxiety and fear are the most critical psychological factors for insomnia, complicated by children's hidden emotional expression, behavioral substitution for verbal communication in young children, and dual influence of family/social support, making the association difficult to define [13].

Currently, Chinese medical institutions pay insufficient attention to the relationship among medications, sedation, and pain. Existing pediatric palliative care

outcome measurement frameworks primarily cover physical, psychological, spiritual, and social domains without requiring pharmacokinetic monitoring. Even individualized care plans only document medication use without tracking blood concentrations or impacts on sleep and pain [16]. This difficulty in distinguishing sedation origins amplifies decision-making challenges, leading to issues such as blind dose reduction or maintaining ineffective doses, potentially compromising pain control while overlooking overdose risks. Regarding the unresolved question of whether anxiety/fear are the key psychological factors for insomnia, scarce child-specific psychological assessment resources limit individualized sleep monitoring and intervention [20].

To address this, we recommend: (1) incorporating overnight pulse oximetry into routine care for PPC patients with severe conditions or respiratory insufficiency to improve detection of opioid-related sleep disruption [21]; (2) strengthening combined management of morning glucocorticoid administration and family-assisted sleep pattern documentation through standardized sleep logs (recording sleep onset latency and nocturnal awakenings) to monitor circadian changes; and (3) enhancing collaboration between PPC teams and sleep specialists to provide specialized guidance for polypharmacy patients, ensuring treatment efficacy while minimizing negative medication effects on sleep.

4.1.4 Disruption and Management of Medical Procedures, Skeletal Changes, and Positioning Needs

The Consensus confirms that medical procedures (77% consensus), skeletal changes (86% consensus), and positioning needs (88% consensus) are common triggers for nocturnal awakenings and sleep problems in PPC. Vital sign monitoring and medication administration frequently interrupt sleep; neuromuscular disease-related skeletal deformities and pain, combined with passive positioning causing local compression and circulatory impairment (numbness, tingling), significantly reduce sleep quality and duration, affecting disease recovery and symptom control. The Consensus provides targeted management principles: optimizing nursing operation sequencing to minimize nocturnal disruptions for medical procedures; emphasizing early identification and coordinated pain control for skeletal change-related sleep disturbances; and recommending individualized positioning strategies to enhance sleep quality.

In Chinese clinical practice, pediatric ward nursing staff ratios average 1:2.5 per bed, with nighttime nursing operations concentrated in peak periods that create compounded “operation-sleep disruption” effects. Early identification of skeletal abnormalities in neuromuscular disease patients relies on imaging, resulting in low early detection rates. In positioning management, only 25% coverage of custom pressure-relieving mattresses adapted for children’s body size is available, with most using adult substitutes [17].

Therefore, for Chinese PPC patients, we recommend: (1) implementing concentrated care models that consolidate necessary nighttime operations within 30

minutes [18]; (2) improving early identification rates through physical examinations combined with simple muscle strength assessment scales; and (3) developing and promoting pediatric positioning assistance toolkits combined with family-involved turning schedules every 2 hours. This creates a management pathway adapted to domestic resources across operational procedures, assessment methods, and assistive devices to effectively improve PPC sleep disruption.

4.1.5 Impact and Management of Opioid-Induced Respiratory Changes and Glucocorticoid Use

The Consensus indicates that sleep disruption correlates with opioid-induced respiratory changes (78% consensus), and glucocorticoid use associates with circadian rhythm disturbances (79% consensus). In Chinese PPC patients, polypharmacy is common, with surveys showing over half of children receiving two or more medications simultaneously for pain, anxiety, and insomnia. However, the current pediatric palliative care outcome measurement framework covers physical, psychological, spiritual, and social domains without requiring pharmacokinetic monitoring. Even individualized care plans only document medication use without specialized tracking of blood concentrations or sleep/pain impacts [16], making it difficult to distinguish whether sedation originates from drug synergy, drug characteristics, or pain relief. This amplifies decision-making difficulty, leading to blind dose reduction or maintaining ineffective doses that may compromise pain control or overlook overdose risks. Nighttime pulse oximetry, a key method for identifying respiratory changes, has low overall coverage, resulting in delayed detection of opioid-related sleep disruption [19]. While morning glucocorticoid administration is recognized as reasonable, dynamic monitoring methods for children's sleep-wake cycles remain limited, and pediatric sleep specialist resources are insufficient to meet individualized sleep monitoring and intervention needs [20].

To address this, we recommend: (1) incorporating overnight pulse oximetry into routine care for severe and respiratory-insufficient PPC patients to improve detection of respiratory change-related sleep disruption [21]; (2) strengthening combined management of morning glucocorticoid protocols and family-assisted sleep pattern documentation through standardized sleep logs; and (3) enhancing collaboration between PPC teams and sleep specialists to provide specialized guidance for polypharmacy patients, ensuring therapeutic efficacy while reducing negative medication effects on sleep.

4.1.6 Sleep Problems Among Parents/Caregivers and Family Support Strategies

The Consensus emphasizes that most parents/caregivers of PPC patients experience sleep problems, primarily due to concerns about unexpected death during sleep (82% consensus). PPC emphasizes holistic family-centered care, with families enduring prolonged treatment processes that impose heavy caregiving tasks

and financial burdens while increasing vulnerability to anxiety and depression, which directly affect caregivers' sleep quality and indirectly disrupt children's sleep and disease management. Research confirms that caregiver physical and mental health correlates with child outcomes; when caregivers experience insomnia and fatigue, caregiving quality declines significantly, creating a potential chain reaction of caregiver sleep problems, reduced care quality, and child deterioration [24].

In Chinese clinical practice, PPC services focus primarily on child treatment, with screening and intervention for caregiver sleep problems remaining weak. Caregivers have limited access to psychological support resources and nursing guidance [23]. Therefore, we recommend integrating caregiver sleep and psychological status assessment into routine PPC practice, evaluating concerns about unexpected death, and strengthening family-centered interventions through lectures and one-on-one consultations to provide nighttime safety care skills, alleviating caregiver anxiety. Linking with psychology and social work departments can provide targeted psychological support and sleep intervention recommendations for caregivers with sleep problems, reducing their burden and improving overall care effectiveness.

4.2.1 Recognition of Sleep Problem Importance and Early Assessment Recommendations

The Consensus establishes broad agreement (92% consensus) on the importance and necessity of addressing sleep problems in treatment planning, recognizing them as a significant symptom burden that exacerbates fatigue, pain, and quality-of-life decline for both patients and families. Sleep assessment should be integrated into routine PPC practice with emphasis on early identification. Experts also strongly agree (98% consensus) that comprehensive evaluation during initial assessment should consider sleep problem comorbidities and all sleep disorder types to build personalized intervention strategies [25].

Chinese PPC includes both malignant conditions (e.g., pediatric oncology) and non-malignant conditions (e.g., neuromuscular diseases with high sleep problem risk due to immobility and complications), yet primary institutions often overlook sleep issues in non-malignant diseases. The Chinese PPC service system remains immature, with primary-level facilities lacking professional assessment personnel and tools. Therefore, early assessment should prioritize establishing screening mechanisms in tertiary hospital PPC specialties, leveraging telemedicine to disseminate assessment protocols to primary care [26].

For localization, sleep assessment should be incorporated into Chinese PPC practice standards, requiring rapid questionnaire screening in specialty clinics focusing on key symptoms like sleep onset difficulties. A "Sleep Problem Recognition Pocket Guide" should be developed for primary care physicians to identify high-risk signals, with suspected cases referred promptly, establishing a primary screening and tertiary referral model.

4.2.2 Standardized Sleep Questionnaires and Parent Sleep Diaries for Precise Assessment

The Consensus confirms that standardized sleep questionnaires and sleep diaries are core tools for PPC sleep assessment, with 87% of experts endorsing questionnaires for rapidly obtaining overall sleep status and 97% supporting diaries for dynamic sleep detail recording. The Consensus clarifies the value of combining both methods, with questionnaires enabling quick screening and diaries capturing detailed patterns, and their combined use enhancing assessment precision.

Internationally common tools such as the Children's Sleep Habits Questionnaire (CSHQ) and Pediatric Sleep Questionnaire (PSQ) were developed based on Western child samples, with some items mismatched to Chinese family parenting culture [27]. International emphasis on daily parental recording conflicts with time constraints in Chinese dual-income families, reducing diary completion compliance and hindering implementation of "family-centered" care concepts in primary practice. Although domestic research has revised the CSHQ for localization, it can be promoted as a PPC-specific standardized questionnaire [28].

Therefore, we recommend prioritizing brief questionnaires adapted to local culture, supplemented by simplified sleep diaries containing only core items, with digital tools to improve completion rates. Tertiary hospital PPC specialties can establish questionnaire and diary assessment archives linked to electronic medical records, while primary institutions can connect with superior hospitals to balance assessment quality and resource consumption.

4.2.3 Clinical Assessment and Intervention for Psychological Correlates of Sleep Problems

The Consensus indicates that PPC sleep problems commonly associate with anxiety and depression, with 80% of experts agreeing that psychological status should be investigated during sleep assessment and 87% confirming bidirectional associations between sleep and depression/despair, requiring interventions addressing both sleep improvement and psychological support [29].

Chinese PPC patients exhibit unique psychological characteristics: children with malignant diseases tend to develop medical procedure-related anxiety, while those with non-malignant conditions often suffer from low self-worth. These challenges are exacerbated by insufficient parental awareness and low acceptance of professional psychological intervention, compounded by scarcity of PPC-experienced child psychology specialists [30].

To address this, we recommend a multi-tiered intervention system: (1) assessment using dual-dimensional parent-report and clinician-observation modes; (2) intervention stratification based on family acceptance, ranging from "embedded psychological support" to brief cognitive-behavioral therapy; and (3) resource

integration through internet platforms and training specialist nurses as “psychological support liaisons” to improve service accessibility.

4.2.4 Indirect Indicators and Comprehensive Assessment for Non-Communicative Patients

The Consensus emphasizes that for PPC patients unable to express themselves clearly (e.g., cerebral palsy, severe neurodevelopmental disorders), sleep disturbances must be assessed through indirect indicators (crying, physiological changes) and potential factors (pain, medication side effects), with 80%-100% agreement. Additionally, 93% of experts stress the central importance of pain monitoring, while 79% agree on the association between glucocorticoids and circadian rhythm disturbances.

Portable devices can monitor physiological indicators combined with behavioral observation scales for screening, while standardized pain and medication impact assessments should be implemented. Drawing on international experience, palliative care quality collaboratives and pediatric palliative improvement networks can conduct multi-center quality improvement projects to validate and refine assessment tools, thereby building comprehensive, scientific quality evaluation systems [31].

4.2.5 Systematic Assessment of Sleep Behavior Characteristics and Circadian Patterns

The Consensus stresses that systematic assessment of sleep behavior characteristics (e.g., sleep onset latency, sleep maintenance duration) and circadian patterns (e.g., fixed bed/wake times) forms the foundation for sleep intervention and holds important clinical value for improving sleep quality [32].

In China, PPC patients can use the “PPC Child Sleep Behavior Assessment Form” to record sleep onset latency, maintenance time, and sleep efficiency, combined with parent diaries and clinician observation for continuous evaluation. The “Patient Circadian Timeline” can quantify schedule fluctuations, identifying irregular patterns such as sleep onset time standard deviation >30 minutes. Intervention should be stratified: tertiary hospitals can incorporate assessment results into individualized treatment, establishing fixed bedtime routines for those with >30 -minute sleep latency and using gradual adjustment for those with high schedule variability. Primary institutions can implement “Family Circadian Guidance Programs,” developing feasible schedules based on parental availability and reinforcing compliance through online check-in groups.

4.2.6 Controversies and Clinical Recommendations on Sleep Study Referrals and Monitoring Devices

The Consensus clarifies that sleep studies (e.g., polysomnography) for PPC patients should be limited to cases with clear therapeutic goals (e.g., suspected

sleep apnea), with 94% expert consensus. However, no consensus was reached on actigraphy and video monitoring applications.

In China, pediatric polysomnography equipment is scarce and access limited, yet sleep apnea is not uncommon in PPC populations, necessitating priority referral indications. Actigraphy is cost-effective for long-term monitoring, while video monitoring is limited by low parental acceptance and insufficient primary-level analysis capacity, though research demonstrates its reliability in providing monitoring data [33].

Therefore, sleep study referrals should be strictly limited to indications such as moderate-to-severe sleep apnea, with primary-level screening through referral checklists and green-channel referral pathways. Actigraphy is recommended for long-term efficacy evaluation during medication adjustments [34]. Video monitoring should be confined to hospital settings with strict informed consent and data security management protocols.

4.2.7 Dynamic Assessment Strategies, Longitudinal Research Value, and NIV-Specific Recommendations

The Consensus proposes dynamic assessment of PPC sleep problems (e.g., reassessment during disease changes), with 90% expert endorsement. It emphasizes the value of longitudinal research in clarifying sleep problem evolution, with 89% and 87% of experts respectively agreeing that long-term non-invasive ventilation (NIV) patients require routine sleep breathing reassessment.

Chinese PPC patients primarily rely on outpatient follow-up, facing challenges of irregular follow-up intervals, absent primary-level assessment tools, and insufficient longitudinal evidence. Small-scale studies suggest sleep breathing events may worsen with disease progression, yet NIV equipment has low penetration rates in China, and primary-level assessment capacity remains weak [35].

We recommend building a tiered dynamic assessment system: stable patients undergo regular questionnaire and diary assessments, while disease changes trigger emergency assessment within 48 hours using digital tools and outpatient/home linkage mechanisms to enhance monitoring efficiency. Regional medical centers should establish specialized assessment centers, strengthen technical training for primary-level personnel, and standardize NIV post-use assessment frequency and parameter adjustment protocols.

4.2.8 Parental Sleep Problems Related to Child Sleep Changes and Family Support Strategies

The Consensus emphasizes that PPC child sleep problems easily cause parental sleep deprivation, with 87% and 91% of experts respectively agreeing that parental sleep status should be investigated and family support interventions provided, while 82% identify parental concerns about nocturnal disease deterioration as the primary cause of their sleep problems [36].

Chinese PPC parents bear heavy nighttime caregiving tasks while experiencing intense anxiety about their child's condition, with weak family support systems—only a small portion can obtain grandparental assistance, community support coverage is low, and professional resources are severely insufficient [37].

Localization efforts should focus on three levels: (1) assessment using validated palliative care parent sleep quality questionnaires for baseline and monthly dynamic evaluation [38]; (2) intervention through a comprehensive support system addressing disease concerns, caregiving task sharing, and psychological support; and (3) resource protection by incorporating family sleep support into child welfare policy frameworks, clarifying insurance pathways, and encouraging social participation to improve service accessibility and sustainability.

4.3.1 Multidisciplinary Team-Based Intervention Strategies

The Consensus clarifies that PPC sleep problems require MDT intervention, integrating PPC, sleep medicine, psychology, nursing, and other specialties to develop individualized protocols combining non-pharmacological and pharmacological approaches. Over 90% of experts endorse this model for improving intervention precision and addressing multifactorial causes (pain, medication side effects, psychological anxiety), compensating for single-discipline limitations [39].

Chinese PPC disease patterns primarily involve neuromuscular diseases and pediatric oncology with complex etiologies. However, MDT resources are unevenly distributed—only a few tertiary hospitals have PPC MDT teams, generally lacking sleep medicine specialists. Primary institutions without PPC physicians often lack professional identification and preliminary intervention capacity for PPC sleep symptoms, leading to delayed referrals.

MDT teams should be tiered: tertiary hospitals should have PPC physicians leading multidisciplinary members in developing stratified protocols (e.g., oncology patients with pain specialists, cerebral palsy patients with rehabilitation specialists). Primary-level facilities can establish “1+N” remote linkage models, with primary pediatricians as core contacts linking to tertiary PPC MDT teams through regional collaboration platforms, while opening green channels for emergency cases to provide immediate professional guidance for PPC sleep problems.

4.3.2 Cognitive Behavioral Therapy for Insomnia (CBT-I), Sleep Hygiene, and Pharmacological Treatment

The Consensus establishes CBT-I as first-line non-pharmacological intervention for PPC insomnia, with 86% of experts endorsing its effectiveness through sleep cognition adjustment and pre-sleep behavior modification. Sleep hygiene optimization (fixed schedules, sleep environment) is fundamental, with 97% expert agreement. When CBT-I is insufficient, individualized pharmacological protocols should be developed based on age, underlying disease, and drug interactions

[40].

Chinese PPC insomnia management faces localization challenges: international standard CBT-I is time-consuming and conflicts with dual-income family schedules, while young children have limited acceptance of cognitive interventions. Independent sleep training also conflicts with the cultural reality that nearly half of Chinese children co-sleep. Domestic research shows simplified family-based CBT-I achieves comparable efficacy with higher parental acceptance. Pharmacologically, although zolpidem and melatonin are commonly used, PPC-specific pharmacokinetic data are lacking [41].

We recommend: (1) age-simplified CBT-I using gamification for young children and task-based check-ins for school-age children with compressed cycles; (2) sleep hygiene optimization using gradual separation strategies; and (3) tiered pharmacological protocols based on insomnia severity, with strict medication reporting and monitoring systems at primary institutions to ensure safety.

4.3.3 Complementary and Alternative Medicine: Mechanisms and Clinical Application

The Consensus indicates music therapy can serve as an adjunctive intervention for PPC sleep problems, with 78% of experts endorsing its indirect sleep improvement effects through autonomic nervous system modulation and anxiety reduction, emphasizing operation by certified therapists and MDT safety assessment while prohibiting unproven herbal supplements [42].

Chinese parents show significant regional differences in complementary and alternative medicine (CAM) acceptance (urban preference for music therapy, rural preference for traditional Chinese massage), but certified therapists are scarce, with primary-level practitioners often being non-professional healthcare staff, and massage can cause skin injury. Research demonstrates traditional Chinese massage can improve sleep efficiency and reduce anxiety scores [43].

For localization, we recommend: (1) establishing a clear list endorsing traditional Chinese massage and folk music therapy while prohibiting unregistered herbs; (2) MDT pre-assessment of applicability (e.g., contraindicating massage in coagulation disorders); and (3) establishing effectiveness monitoring tables, with protocol adjustment if no improvement.

4.3.4 Benzodiazepines and Antihistamines: Pharmacological Characteristics and Controversies

The Consensus clarifies that benzodiazepines (e.g., diazepam) and antihistamines (e.g., chlorpheniramine) require strict limitation due to dependence and cognitive impairment risks, with 84% of experts agreeing they should only be used short-term when other interventions fail, excluding contraindications such as respiratory depression. The controversy centers on the “efficacy-risk ratio” (short-term effectiveness but long-term functional impairment).

In Chinese PPC patients, benzodiazepine usage rates are high and conveniently used by primary institutions, while antihistamine misuse causes frequent adverse reactions [44]. Research confirms long-term diazepam use leads to cognitive decline and withdrawal symptoms, while chlorpheniramine can shorten sleep onset but causes prominent daytime sedation.

We recommend strict medication control: benzodiazepines limited to short-term emergency use for acute insomnia, preferably replaced by melatonin combined with CBT-I; antihistamines prohibited for routine sleep aid, only applicable short-term with clear indications. Risk management should implement dual-prescription verification systems, real-time primary-level reporting systems, and municipal centers issuing regular risk warnings.

4.3.5 Melatonin: Physiological Functions and Individualized Selection

The Consensus emphasizes melatonin improves PPC sleep by regulating circadian rhythms and shortening sleep onset latency, with 97% of experts agreeing on individualized formulation selection based on sleep patterns (e.g., sleep-onset difficulty type). Additionally, 75% of experts express concern about formulation purity, requiring USP-certified products in the U.S. and licensed products in other countries.

China's melatonin market suffers from ambiguous regulation, with over half of parents confusing health supplements with pharmaceuticals, and lack of child-specific formulations leads to dosing inaccuracies [45].

We recommend implementing individualized protocols: selecting appropriate formulations based on sleep problem type, with dose adjustments for special populations. All melatonin use should prioritize pharmaceutical products verified through official platforms, with regular evaluation and multidisciplinary review throughout the supervision process.

4.3.6 Gabapentin: Mechanisms and Caregiver Sleep Considerations

The Consensus proposes gabapentin improves sleep in PPC patients, particularly those with increased neuronal excitability, by inhibiting neuronal overexcitation and alleviating neuropathic pain, with 87% of experts endorsing it as adjunctive therapy for "pain-sleep comorbidity." Additionally, 91% of experts emphasize concurrent caregiver sleep intervention [46].

Chinese PPC patients using gabapentin face dosing irregularities and high adverse reaction rates in primary institutions. Standardized gabapentin use significantly improves sleep, while providing sleep guidance and respite services effectively extends parental sleep duration.

We recommend: (1) tiered gabapentin dosing based on symptom severity with strict hepatic/renal function monitoring; and (2) establishing multi-level support systems providing non-pharmacological interventions for children while in-

tegrating community respite services and professional sleep guidance for parents to comprehensively improve family sleep status.

6 Strengths and Limitations

6.1 Strengths

Methodologically, the Consensus employs systematic reviews and meta-analyses as its core evidence base, screening high-quality evidence through authoritative database searches, while using a modified Delphi method for two rounds of global interdisciplinary expert consultation involving experienced specialists from 18 countries. Through blinded voting and optimization of controversial items, 53 consensus recommendations were formulated, effectively integrating evidence-based medicine with global clinical experience, avoiding limitations from single evidence sources or regional perspectives, and ensuring reliability and broad representability.

In content, as the first global consensus focused on PPC sleep problems, it establishes a pioneering “definition-assessment-treatment” tripartite framework, clearly defining multifactorial pathogenic characteristics, core influencing factors, and bidirectional associations (e.g., sleep-emotion, sleep-caregiver burden interactions), filling a long-standing systematic guidance gap. The Consensus upholds PPC’s “family-centered” holistic care philosophy by incorporating caregiver sleep problems into management scope, clarifying core triggers of caregiver sleep disturbances and their impact on care quality, expanding management dimensions. Additionally, the Consensus emphasizes clinical practicality by identifying core assessment tools and processes, the value of MDT collaborative intervention models, and key directions for pharmacological and non-pharmacological interventions, providing actionable guidance for clinical practice.

6.2 Limitations and Challenges

Although the Consensus provides important guidance for PPC sleep management, improvements are needed in detail refinement and localization adaptation, requiring flexible adjustment based on clinical reality rather than negating overall value. Methodologically, using expert voting percentages as consensus criteria without grading recommendation strength or evidence level reduces flexibility for different patient populations with complex conditions. Additionally, although expert composition and evidence sources cover multiple countries, insufficient consideration of healthcare system characteristics and resource accessibility in low- and middle-income countries limits adaptability of some high-resource-dependent recommendations in resource-limited regions.

Content-wise, PPC patients exhibit significant disease heterogeneity. While the Consensus addresses common associations between sleep problems and pain/medication side effects, it lacks disease-subgroup-specific differentiated

strategies, providing insufficient targeted guidance for specific disease sleep problems. Some intervention details require supplementary support, such as specific polypharmacy protocols and simplified non-pharmacological interventions for end-stage patients, which remain undefined and may cause implementation variation across PPC institutions. Such variations can be refined through Chinese PPC clinical experience and future research.

For Chinese PPC clinical practice, consensus implementation faces several adaptation challenges: (1) Institutional level—lack of policy support for MDT models and absence of “sleep-pain-emotion” collaborative management from PPC quality metrics constrains routine MDT implementation; (2) Resource level—limited pediatric sleep specialists and lack of PPC-specific assessment tools/intervention equipment at primary institutions affect implementation efficiency; (3) Cultural level—Chinese PPC families primarily use parental caregivers, with dual-income families showing limited compliance with long-term sleep monitoring, requiring optimization of parental cognition and tool adaptation. Addressing these challenges through improved MDT policies, enhanced primary-level training and remote resource outreach, and development of localized assessment tools and interventions will enhance consensus applicability and promote standardized PPC sleep management development in China.

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