



## Original Article

# The development and psychometric assessment of a questionnaire to assess sleep and daily troubles in parents of children and young adults with severe psychomotor impairment



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## ABSTRACT

**Background:** Children with severe psychomotor impairment (SPMI) often experience sleep disturbances that severely distress both the child and his or her parents. Validated questionnaires for the assessment of parents' distress related to their child's sleep disturbances are lacking.

**Methods:** We developed and validated a new questionnaire, the HOST (*holistic assessment of sleep and daily troubles in parents of children with SPMI*) to assess the effect of the sleep disturbances in children with SPMI on their parents. The questionnaire was developed based on published data and expert opinion, and it was refined via direct consultation with affected parents. Its psychometric characteristics were assessed in a sample of parents of 214 children with SPMI. It was retested using a random subsample of the participants.

**Results:** Explorative factor analysis revealed that the HOST was composed of four scales. Fit indices, item analysis, and convergent validity (coherence with preexisting instruments of sleep disturbances and health status) were adequate. Retest analysis ( $n = 62$ ) revealed high stability of the HOST questionnaire and adequate replication validity.

**Conclusion:** Sleep-related difficulties significantly impact the sociomedical characteristics of the parents of children with complex neurologic diseases. Typically, parents are severely affected in various aspects of daily life (i.e., medical health, social life, professional life). The HOST proved to be a valid, reliable and economical assessment tool of sleep-related difficulties in parents and relatives of children with SPMI. The HOST is capable of identifying individuals and specific areas requiring intervention.

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## 1. Introduction

A unique feature of pediatric populations is that the health and well-being of parents can be strongly affected by the medical condition of their children. This statement is especially true in highly disabling pediatric conditions such as severe psychomotor impairment (SPMI). SPMI is associated with multiple diseases, including childhood neuromuscular disorders (e.g., muscular dystrophies, spinal muscular atrophies), cerebral palsy, and neurodegenerative and metabolic diseases (e.g., mucopolysaccharidosis, neuronal ceroid lipofuscinosis). These children are impacted by both

intellectual impairments and physical disabilities. The occurrence of SPMI in children and adolescents is 1–3% [1,2]. This condition most often results from perinatal insults (i.e., prematurity, asphyxia), syndromes, and other genetic or metabolic diseases [3]. Approximately 50–80% of these children experience sleep disturbances (i.e., delayed sleep onset, disturbed sleep–wake cycles, difficulties in waking [4,5]), which result in restlessness and hyperactivity during the day [6,7]. There are various factors inherent to the underlying conditions provoking sleep disturbances in children with SPMI. On the one hand, there are several physical disabilities, including children's impaired ability to reposition their bodies, combined sensory and perceptual impairment, reduced natural melatonin secretion, or epilepsy which may contribute to SPMI. However, on the other hand, disturbed and altered cognitive processes (e.g., mental, communication, behavioral impairment, overexcitation) that affect sleep may trigger sleep disturbances [4].

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Sleep disturbances not only affect children with SPMI but also the parents of the children, which represents a highly relevant medical and social problem [6,8–10]. The majority of caregivers report that their own sleep quality is poor, which may cause fatigue, sleep problems, somatic complaints, depression, and other psychiatric disorders such as anxiety disorders or affective disturbances [11–13]. In one study, 74% of the parents of children with SPMI reported that their quality of life (QoL) or that of the child's healthy siblings was moderately to severely affected by the care needs or restrictions in everyday life related to the child's disease [14]. In a recent study by Wayte et al. [15], 40% of the mothers of children with cerebral palsy reported poor sleep quality; of whom, 44% endorsed depressed mood. Pediatric and maternal sleep disturbances were significantly correlated. In contrast to children with cerebral palsy, children with SPMI are unable express their sleep problems. Another study investigated sleep-related troubles in children with intellectual disabilities and their parents [16]. The author's report higher levels of maternal stress and depression and lower maternal well-being in mothers of children with autism compared to mothers with normally developed children [16]. It is important to note that these children do not have physical impairments.

Children with SPMI experience physical disabilities and cognitive impairments, which likely result in increased parental concerns and troubles with pediatric sleep and nighttime care. There is little information available regarding sleep disturbances in the parents of children with SPMI. Furthermore, the conceivable consequences of daytime sleepiness, social life, and family functioning remain unclear.

The direct effect of sleep disturbances in pediatric SPMI on the sleep patterns and daily troubles of the affected children's caregivers has not been well-studied [11,12,17,18]. Objective and efficient measures of sleep disturbances and daily troubles in parents with handicapped children are lacking and are urgently needed. The validity of questionnaires used in published studies that assess parental burden generally is low. The investigators of these studies adapted preexisting pediatric assessments to their parent samples; however, there was no explicit reevaluation or recalibration of these instruments [19]. The use of these tools to assess sleep disturbances and daily troubles is not meaningful; they were developed for use in healthy populations (families and parents without handicapped children). However, these tools do not necessarily reflect the effect that a child's disease has on the sleep patterns of the parents (i.e., the necessity of permanent caregiving and the sorrows and fears of the parents). To assist clinicians confronted with family sleep problems and enable targeted intervention, it is important to assess the effect of the sleep problems in children with SPMI and the worries of their parents regarding the children's diagnoses and development on each of the parents' functioning. In particular, there is no instrument that addresses sleep and the problems in everyday life that result from sleep disturbances to date (i.e., physical and mental functioning, partnership, social contacts, effect on job performance).

The aim of our report was to assess sleeping patterns and the QoL in parents of children with SPMI. We developed and validated an assessment tool for this purpose, called the HOST (*holistic assessment of sleep and daily troubles in parents with children with SPMI*) questionnaire.

## 2. Methods

We conducted a multicenter, questionnaire-based, cross-sectional survey for parents of inpatients and outpatients with severe cognitive and psychomotor impairments due to severe neurologic or metabolic disease or related to a congenital or genetic syndrome.

### 2.1. Patient recruitment

Parents and patients were recruited from three inpatient institutions (Children's Hospital Datteln, Datteln, Germany; Short-term Home "Kleine Oase Datteln"; and Children's Hospice Balthasar in Olpe, Germany) and one outpatient facility (Paediatric Palliative Care Team Datteln, Germany). Inclusion criteria were as follows: (1) patients presenting at one of the listed facilities between July 2008 and January 2010, (2) children or adolescents diagnosed with SPMI, (3) age ranging from neonate to young adulthood (zero days–25 years), and (4) parents or caregivers who are able to adequately communicate in German either verbally or in writing.

All of the patients who satisfied the inclusion criteria were contacted by phone and informed of the aims of our study. If the patient was eligible and the parents consented to participate in the study, they were sent a set of questionnaires, a letter of intent, a consent form, and a prepaid return envelope. All parents who did not return the questionnaires after 2 weeks were contacted via phone by the study coordinator (ALT). Parents who did not respond to the phone call did not participate in the study.

### 2.2. Introducing a new assessment tool: the HOST questionnaire

The HOST questionnaire was designed to evaluate the effects experienced by the parents or caregivers of children with SPMI-related sleep disturbances. The basic concept and structure were adapted from the Pittsburgh Sleep Quality Index (PSQI), an internationally validated assessment tool recommended by the German Sleep Society to assess adults with sleep disturbances. For use in the parents of children with SPMI, we modified the test items to reflect the specific life restrictions and mental or somatic distress experienced by affected parents and the effect of their child's disease on parents' sleep (i.e., due to the permanent care needs of the child and the sorrows, worries, and fears of the parents).

The HOST is meant to be completed by parents, answering questions regarding their own sleep problems and the disruption of their lives resulting from their child's sleep problems during the preceding 4 weeks. In the HOST, the construct (disturbed) sleep addresses this family problem using a biopsychosocial model. In contrast to the PSQI, the HOST questionnaire allows for the specific assessment of sleep-related impairments in parents of a handicapped child. The HOST also allows the parents' nighttime disruption due to the amount of time required to care for their child to be mapped. In addition, the HOST asks for data regarding family changes and a variety of problems (i.e., partnership, social contacts, effect on job performance) resulting from the sleep disturbance of the parent or the child. This information is essential to appropriately treat and support these clients.

The HOST was developed in four stages: (1) a comprehensive literature review provided an overview of the current state of research and comprehensive standards (i.e., existing tools such as the PSQI), which resulted in the first draft of the HOST; (2) interviews with three pediatric experts on sleep and sleep disorders, which resulted in the second draft of the HOST; (3) interviews with 20 parents of children with SPMI and sleep disturbances (pretest) to test the second draft of the HOST for understandability, significance of meaning, clarity, and feasibility, which resulted in a preliminary final version of the HOST; and (4) an analysis of the pretest HOST data, which resulted in the final version of the HOST.

#### 2.2.1. Literature review

The literature review has been previously published [4]. It demonstrated that sleep disturbances in children with SPMI are a significant clinical problem for the affected child and his or her parents and family. It is obvious that a suitable and validated questionnaire for the assessment of the disruption in parents' lives

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