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Optimizing an eHealth insomnia intervention for children with neurodevelopmental disorders: a Delphi study

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ABSTRACT

Insomnia, which is related to daytime deficits and is a common problem for children with neurodevelopmental disorders (NDDs), is often successfully treated with behavioral strategies. However, there are barriers to accessing these treatments, and there has been little research examining what these interventions need to be usable and effective. The goal of this study was to gain consensus from experts in the field on the key components of an eHealth, parent-implemented, intervention program aimed at improving sleep in children with attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, and fetal alcohol spectrum disorder. This was achieved using the Delphi method, which involves asking participants to respond to open-ended questions about a topic of interest and then, in iterative rounds, to rate the recommendations that were made by the group. In the current study, participants (27 responders in the first round, 21 in the second, and 18 in the third) rated a total of 131 recommendations. Of those 131 recommendations, 52 items had high importance and high consensus and were deemed to be priority items to consider for creating an eHealth, parent-delivered, behaviorally based intervention for insomnia in children with NDD. Furthermore, 75% (n = 84) of the 112 recommendations from the first round were believed to be applicable across all 4 NDD groups, thus providing evidence of the potential for a transdiagnostic intervention.

Insomnia, which is defined as difficulty falling asleep, staying asleep, and/or waking too early in the morning, is experienced by approximately 20% of typically developing (TD) children and upwards of 80% in children with neurodevelopmental disoders (NDD)[1–3] In TD children, poor sleep has been found to be associated with numerous daytime consequences, including problems with behavior such as rule-breaking and impulsivity,[4–7] cognitive functions such as memory and attention,[5–8] social behavior,[7] and emotional regulation.[4,8] For children with NDD, many of the areas affected by sleep (eg, executive functioning, social behavior, emotional regulation) are already areas of impairment,[9] and poor sleep has been demonstrated to be associated with increased symptoms.[10–13] Of great concern, sleep problems are more likely to persist in children with NDD when left untreated compared with TD children.[3] Therefore, there is an impetus to treat insomnia given its high prevalence, impairment, and chronicity.

Insomnia in children can be treated both behaviorally and pharmacologically. The use of medications in pediatric populations (eg, α-agonists, antihistamines, hypnotics) lacks strong empirical evidence, and adverse effects are a common concern.[14,15] Despite this lack of empirical support and parent's preferences for nonpharmacological interventions,[16] children, especially children with NDD, are often treated pharmacologically.[17] Given that insomnia

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in children is often behavioral in nature and behaviorally maintained, it is logical to focus on behavioral strategies as a first line of treatment. For both TD children and children with NDD, behavioral intervention is recommended by pediatric sleep researchers and clinicians prior to considering pharmacological treatments.[14,18–20]

Accessing evidence-based behavioral treatment can be difficult because of limited availability,[21,22] excessive wait times,[22,23] and high costs.[21,22] A stepped-care model for treating insomnia in children has been suggested.[23,24] This model is based on the idea that children with the least severe insomnia, which is the greatest proportion of those affected, can be treated with self- and/or parent-administered treatments that are delivered via print/media (eg, pamphlet, internet).[23–25] eHealth interventions (ie, interventions delivered via the Internet[26]) provide a way to reach families who may not otherwise receive treatment because of barriers such as time, money, or geographical constraints. A recent study of an eHealth behavioral intervention for sleep in TD children (6 months to 4 years of age) found that this intervention helped improve the children's sleep and was well-received by the parents who participated.[27] More research is needed on the effectiveness of eHealth interventions for treating sleep problems in both TD children and children with NDD. In fact, to our knowledge, there are currently no published studies that have evaluated an eHealth intervention for insomnia in children with NDD.

Behavioral strategies that are used to treat insomnia in children (whether delivered in a face-to-face context or via eHealth) include providing psychoeducation to parents/caregivers (hereafter referred to as parents), implementing healthy sleep practices, establishing bed and wake times and positive bedtime routines, and using specific behavioral interventions (eg, faded bedtime with response cost, graduated extinction). There is a paucity of literature regarding treatment of insomnia in children with NDD. Although there is evidence available that highlights the most common behavioral interventions for insomnia in TD children, modifications are needed to apply to children with NDD. This was confirmed in a recent systematic review, which identified and evaluated 40 studies with parent-delivered behavioral sleep interventions for children with NDD.[28] The review also suggested applying a transdiagnostic approach to treatment of insomnia in children with NDD.

There is a growing interest within the field of sleep in the utility of transdiagnostic intervention. Transdiagnostic treatment aims to apply a common set of techniques across populations, with a focus on treating the symptoms reported as opposed to tailoring specifically to each individual diagnosis.[29] Transdiagnostic treatment for insomnia has been applied in adults with psychiatric disorders,[30] as well as adolescents with sleep and circadian problems.[29] However, transdiagnostic approach to treatment of insomnia in children with NDD, to our knowledge, has not been developed. Given that there are commonalities across NDD populations, and also with TD populations, for both sleep problems targeted and behavioral sleep interventions that are implemented, a transdiagnostic approach may be feasible.[28] There is currently a lack of consensus on what behavioral strategies are needed to effectively treat insomnia in children with NDD and what modifications to these strategies, if any, are required. Although the evidence suggests that the same behavioral strategies are effective across multiple NDD, there is also a lack of consensus regarding which specific behavioral strategies are effective across NDD and whether a transdiagnostic treatment approach could work in practice.

The aim of the current Delphi study was to generate recommendations and gain consensus from pediatric sleep experts pertaining to the important components required for an eHealth intervention to treat insomnia in children with NDD. A secondary objective of the current study was to examine the feasibility of developing a transdiagnostic intervention by evaluating the applicability of suggested recommendations across NDD populations, specifically attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD). These 4 disorders were chosen, in part, because our funding partner, Kids Brain Health Network, is focused on researching ASD, CP, and FASD. We believed that with the addition of ADHD, these 4 disorders represented a broad range of NDD in terms of etiology; common characteristics; and impact on physical, cognitive, and social abilities.

Methods

Participants

Pediatric sleep experts were nominated to participate in the Delphi study by an advisory team comprised of 12 clinicians/researchers with expertise in sleep in children with NDD in Canada. The criteria to participate in this study were to (1) have a clinical or research appointment at a university or pediatric academic health science center; (2) be specialized in a health field with a focus in sleep and NDD, specifically ADHD, ASD, CP, and FASD; and (3) have contributed to the literature on sleep and NDD through peer-reviewed publications. All clinicians/researchers who were nominated by the advisory team who met these criteria were invited to participate ($n = 50$). Given that this is a relatively small field of research, it was decided that anonymity would be important so that participants would not be influenced by knowing what each participant contributed. As such, responses were submitted anonymously, and the researchers conducting the study were blind as to who completed each round (ie, invitations for each round were sent to all invitees unless they requested to be removed from the list) and their specific contributions.

Procedure and measures

Ethics approval for this study was obtained from the Research Ethics Board of the IWK Health Centre in Halifax, Nova Scotia. All participants provided informed consent and were not compensated for their participation. The 50 potential participants were sent an invitation via e-mail to participate. This invitation briefly explained the goals and the format of the Delphi study. The participants were told that they would be asked to provide their expert opinions about what an eHealth behavioral intervention to improve sleep in children with NDD (specifically, ADHD, ASD, CP, and/or FASD) should include to meet the goal of determining necessary modifications to make typical sleep interventions suitable and effective for use by parents of children with mild to moderate NDD. They were also told that a total of 3 to 5 rounds were expected. Participants were instructed that although it was not completely necessary to participate in all rounds, it was highly recommended, as their responses from each round would help to inform the next round. Participants were given 2 weeks per round to respond and were sent reminder e-mails when 1 week remained and again when 1 day remained. Two weeks following the completion of a response period, the next survey was sent. Invitees could ask at any time to be removed from the mailing list if they wished to withdraw.

Round 1. Upon consenting to participate, participants were asked about what they believed "an online behavioral intervention program aimed at improving sleep in children with ADHD, ASD, CP, and/or FASD should include," were provided with space to offer up to 25 recommendations for inclusion in the intervention, and were asked to indicate which/how many of the 4 NDD they believed each recommendation applied to. The goal was to create a list generated by the experts, and as such, we left the question open-ended so that the participants would not be constrained in their responses. Next,

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