

Sleep Issues

Introduction

Jon Bernstein, MD, PhD presented on the topic of sleep issues in individuals with PMS on a talk entitled “Patient and Caregiver Sleep Quality in PMS”. The focus of his talk was the impact of sleep issues on not just the individual with PMS, but on the family unit as a whole.

Although prior literature suggests that approximately 40-50% of individuals with PMS have sleep issues, there is less research regarding sleep issues in the parents of individuals with PMS. In a recent study conducted by Bernstein’s lab, an estimated 80% of patients were identified to have sleep issues and 90% of parents of patients also were identified to have sleep issues based upon retrospective parent-report questionnaires. It is important to note, however, that these questionnaires are used as screening, not diagnostic, tools. Among the sleep issues identified in patients, approximately 60% were reported to have multiple nighttime awakenings, of which 78% needed parent help falling back asleep and 51% had nighttime awakenings lasting more than 30 minutes. Additionally, parents reported that their children also had difficulty falling asleep. Among parents of individuals with PMS, 78% reported that they were awakened by the child during the night, 41% reported getting an average of less than 6 hours of sleep per night, and 90% reported daytime tiredness. As expected, there was a strong correlation between patient and parent sleep issues, with the strongest correlations being associated with total sleep duration between patient and parent as well as number of nighttime awakenings between patient and parent.

Dr. Bernstein addressed several challenges related to studying sleep issues in individuals with PMS. First, he indicated that individuals with PMS are not routinely assessed for sleep disturbances either by their general practitioner or neurologist/developmental pediatrician. Additionally, he noted that of the few research studies examining sleep issues in PMS, the results are likely biased as families impacted by sleep issues are more likely to participate in a study examining sleep issues. Currently, there are no research studies conducting direct assessment of sleep problems in individuals with PMS and their families, and there are no studies examining effective intervention methods to reduce sleep issues in individuals with PMS. Behavioral and pharmaceutical interventions used for individuals with PMS are based upon other developmental and genetic disorders. For example, sleep coaching has demonstrated effectiveness in Angelman syndrome, and has been used in a few cases of PMS. With regard to pharmaceutical treatment, anti-histamines, melatonin, tricyclic anti-depressants, benzodiazepines, and sedatives all have been used to improve sleep in individuals with PMS.

Overall, sleep problems, including difficult falling and staying asleep, appear to be prominent among individuals with PMS, and these problems likely influence sleep problems in parents/caregivers of individuals with PMS. Yet, sleep problems are not typically formally evaluated among patients, even though their treatment may have a positive impact on the individual with PMS and his/her family.

Identified Problems

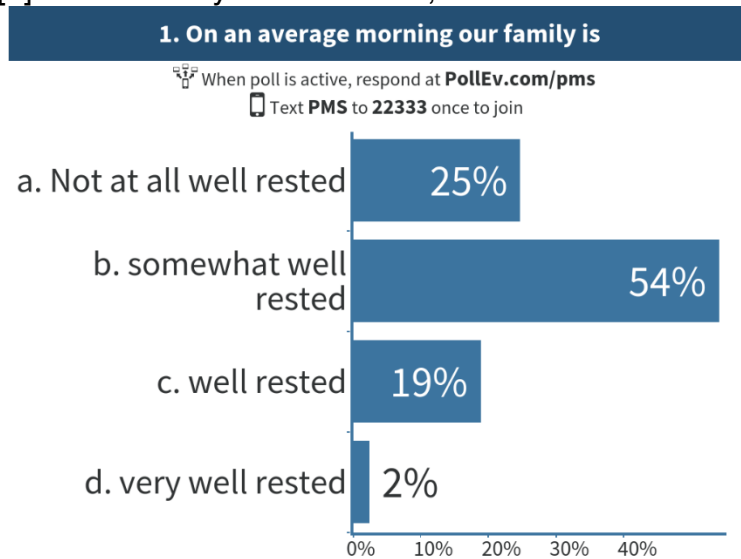
1. The pharmacological and behavioral strategies used to treat my child's issues are overwhelming and I'm not sure they will work or if they are safe.

Based upon the Group discussion, parents indicated that the primary concern regarding their children's sleep issues was related to intervention techniques to improve sleeping. At least 52 parents reported this being a significant concern, with an average rating of 4.6 out of 5. During the Group and Panel discussions, parents noted trying a variety of pharmaceutical and behavioral strategies, including melatonin and behavioral training. However, parents reported that these strategies were inconsistently successful, or, as a few parents expressed, attempted strategies “work[ed] minimally” or had “unreliable results”. Parents not only addressed concerns about the types of medication to use for their children, but also the safety and number of medications used. For example, one parent expressed that her child was using “too many medications” and she had specific “concerns about side effects”, including being “out of it” and “groggy”. Medication usage seemed to be the prominent strategy to treat sleep issues in individuals with PMS, yet parents continued to expressed concerns with “determining [which medication] works and dealing with side effects [of the medication].” Beyond questioning which interventions to use, several families expressed concerns regarding their implementation of these interventions, whether they are behavioral or pharmaceutical. Thus, it appears that parents also are seeking additional guidance from medical practitioners on implementation of sleep interventions. Lastly, a few parents questioned whether changes in diet also could improve sleep in their children.

2. My child's sleep problems are really affecting my quality of sleep and life.

As suggested by Dr. Bernstein's introductory talk, parents from the Poll Everywhere and Group discussion indicated the negative impact of their children's sleep issues on their own sleep. Approximately 38 parents indicated this as a concern, and ranked it as a significant concern (4.5 out of 5). This is consistent with findings from the Poll Everywhere data indicating that only 54% of parents feel “somewhat well rested” on the average morning and an additional 25% feeling “not at all well rested” (see Question 1 graph below). Additionally, parents noted that poor sleep had an overall negative impact on quality of life. For example, several parents described this issue in the following ways: “Both caregiver and child [are] exhausted”, “[Sleep issues are] affecting work life

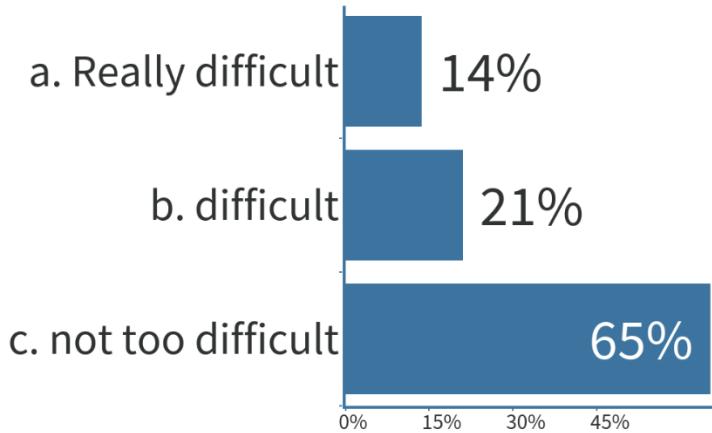
and personal life”, “Parents have poor sleep patterns with long-term effects on health. [It] affects family and work life”, “We are so tired and haven’t slept in year”.



Interestingly, the Poll Everywhere data indicates that only 35% of parents reported that falling asleep was really difficult or difficult from their children, with the remaining 65% reporting that it is not too difficult for their children to sleep (see Question 2 graph below). On the other hand, more parents indicated that it is difficult for their children to stay asleep. For example, 45% of parents reported that it was really difficult or difficult for their children to sleep (see Question 3 graph below). Another 35% indicated that it was not too difficult, and 20% indicated that it was not difficult at all. There are several possible explanations for these findings. For example, the majority of individuals with PMS do not have sleep issues; however, those that do are impacting the lives of their families significantly. Or, sleep issues may be common among individuals with PMS, but many families have implemented successful intervention to improve sleep.

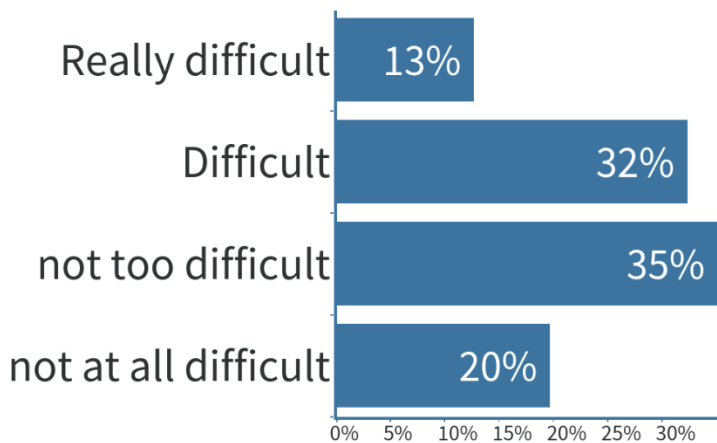
2. How difficult is it for your child to fall asleep at night?

When poll is active, respond at [PollEv.com/pms](https://www.poll-ev.com/pms)
Text **PMS** to **22333** once to join



3. How difficult is it for your child to stay asleep?

When poll is active, respond at [PollEv.com/pms](https://www.poll-ev.com/pms)
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3. It is unclear whether my child should participate in a sleep study or not.

During the Group and Panel discussions, parents noted several questions regarding their children’s participation in sleep studies. At least 37 parents noted that this was a concern and it was rated to be a moderate concern with a ranking of 3.9 out of 5. Specific questions about sleep studies included, but were not limited to: the effectiveness/quality of results, toleration of equipment, additive value of potential sleep disorder diagnosis, importance of sleep study for determination of intervention methods, inconsistent interpretation across providers. Other parents also noted having concerns about whether the “new environment could be stressful and worsen sleep problems”. Additionally, parents also expressed concerns related to sleep specialists being able to appropriately provide care for their children with PMS. For example, one parent said,

“Sleep doctors are ill-prepared for our kids. Too many try this or that medication or order more sleep studies. Doctors do not offer enough help or advice to manage”.

4. My child’s sleep problems seem to be impacting his/her daily functioning.

Parents indicated that their children’s sleep issues were negative impacting their daily functioning, including their participation in school and therapy. This concern was rated to be a moderate concern (4.1 of out 5) and at least 21 parents reported this as a concern during the Group discussion. For example, one parent reported their child’s “problem with learning or behavior after poor sleep”. Other families noted increased irritability in their children following a poor night of sleep, and questioned whether this would have long-term consequences on learning and attention at home and in school. Additionally, some parents also addressed specific concerns about their children’s activities when they were awake during the night (e.g., elopement).

Proposed Solutions

1. Determination of evidence-based treatments for sleep issues in individuals with PMS.

Research should be focused on determining the best interventions to improve sleep issues in individuals with ASD. Both behavioral- and pharmaceutical-based interventions should be considered. Additionally, it may be helpful to investigate the nature of these sleep disturbances, as this may inform the most appropriate interventions for specific sleep issues. Furthermore, current and future research results regarding sleep intervention in PMS should be disseminated more widely to the public so that parents and providers may more readily access this information.

2. Increased awareness of impact of child’s poor sleep on parent’s sleep and quality of life, and development of strategies to support parent’s needs.

Although the majority of parents in our Poll Everywhere poll did not indicate that their children had significant sleep issues, the results suggest that for those parents whose children do experience significant sleep issues, their quality of sleep and life are severely impacted. Thus, it is important for greater awareness of the importance of sleep hygiene in both individuals with PMS and parents of individuals with PMS. Although one of the major limiting factors of improved parent quality of sleep is limited research and understanding of most effective intervention for individuals with PMS, it is important for parents to know that sleep issues is a problem that can and should be addressed with an appropriate medical provider. Additionally, medical providers should be aware that sleep issues are relatively common among individuals with PMS and that

the sleep issues impact on the individuals and their families is profound, and thus should not be ignored. Increased awareness may be completed through a number of means, including but not limited to, lay-friendly articles or blog posts on PMSF website, inclusion of sleep issues in available practice parameters and other scientific articles on PMS, and hand-outs for families and medical providers available in print and online.

3. Development of practice parameters regarding sleep issues in individuals with PMS.

Because sleep specialists (and other medical providers treating sleep issues in individuals with PMS) are likely to be less familiar with the PMS population, there is a huge need for this resource. Practice parameters should not only highlight sleep issues among individuals with PMS (i.e., difficulty falling and staying asleep, sleep apnea, night terrors), but also should include detailed guide on appropriate course of treatment (see Proposed Solution 1). For example, a first step may be identifying sleep issues with a general pediatric practitioner and implementing behavioral strategies, whereas later steps may include medication and participation in a sleep study. Because of the relative invasiveness of a sleep study, practice parameters should be thorough on reasons for obtaining a sleep study for a child and its potential benefits and risks. For example, it was noted during the Panel discussion that important information about an individual's sleep (i.e. architecture, latency to fall asleep, number of nighttime awakenings) may be gathered without a sleep study, and thus a sleep study is often not necessary. Thus, it is important to outline this information for providers and families in a more accessible and comprehensive manner. Furthermore, practice parameters should include follow-up interventions for specific sleep study results. For instance, whether a particular finding should necessitate medication, CPAP, and/or behavioral intervention. Practice parameters are intended for medical providers; however, should be accessible to family members and adapted into a lay-friendly guide. The lay-friendly guide also should contain specifics regarding behavioral interventions and strategies to improve sleep hygiene. For example, as Dr. Bernstein noted in his talk, sleep initiation may be improved by darkened rooms, allotting a "wind down time" without electronics at least thirty minutes prior to bed time, and a daily sleep routine.

4. Increased research examining impact of sleep behavior on overall functioning in individuals with PMS and increased awareness of appropriate interventions to improve sleep quality.

There is limited research into the sleep issues in PMS. Research funding should be dedicated into identifying etiology of sleep issues, common sleep disturbances, impact of sleep issues on functioning, and evidence-based interventions (see Proposed Solution 1) in PMS.