



Original Article

The impact of delayed sleep phase disorder on adolescents and their family



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ABSTRACT

Introduction: We investigated the impact of delayed sleep phase disorder (DSPD) on the daily lives of adolescents and their families.

Method: In this qualitative study, six adolescents with DSPD, and six parents were given in-depth interviews. Using thematic analysis, we merged open codes into themes that reflected the impact of the disorder.

Result: We identified five themes: (1) Impact on the adolescents' school and social life: describing the negative influence of DSPD on school performance and friendships. (2) Impact on the parents, feeling guilty and powerless: showing the consequences of many unsuccessful attempts to improve the situation, with a lack of understanding from their social support system. (3) Impact on the family, conflicts, and misunderstanding: describing the negative influence on other family members, family relationships, and home atmosphere. (4) Impact on the parents, being weary of everything: describing the effect on the parents' mood and social life. (5) Factors mediating the severity of impact, of which personal characteristics and school support seemed most important. Themes 2 to 4 were highly interrelated.

Conclusions: Adolescent DSPD not only affects cognitive functioning and mental health but has a much broader impact, also affecting social life, family life, and parental well-being. This information provides new potential points of engagement for therapy, guidance, and support for these families. Greater awareness and recognition of the impact of DSPD is needed on the part of physicians as well as the general population, to increase support and reduce misunderstanding of these adolescents and their parents.

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1. Introduction

Delayed sleep phase disorder (DSPD) is a circadian rhythm disorder in which a person's sleep/wake cycle is delayed with respect to the external day/night cycle. This results in difficulties in falling asleep in the evening and getting up in the morning. Consequently, patients often suffer from the consequences of sleep deprivation during the day. DSPD has the highest prevalence in adolescents because of the natural circadian rhythm shift at this age

[1,2]. The prevalence of DSPD depends on the criteria used to define it; it is estimated that up to five percent of adolescents meet all Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Sleep Disorders (ICSD) criteria for the diagnosis [3–6]. DSPD can further be accompanied by inadequate sleep hygiene and/or chronic insomnia, resulting in even more sleep loss [2].

Previous studies on DSPD in adolescence have shown an association with psychological symptoms (eg, anxiety, irritability, and depressive symptoms) [5,11–14] as well as with school performance [11]. Supplementary research concerning the consequences of DSPD in adolescents has not yet been implemented, but effects in more domains can be expected given the clinical overlap with insomnia disorders and the consequences of sleep deprivation

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[7–10]. Studies on chronic insomnia in adolescents showed diminished social functioning, an increased risk of alcohol and drug abuse [16], and even an association with self-harm and suicidal behavior [16,17,20,21]. One study showed that earlier parental-set bedtimes could help protect against adolescent depressive symptoms and suicidal thoughts [15]. Adolescents with insomnia are less likely to maintain a healthy lifestyle: they engaged in fewer sports activities, had a worse diet, and had less adequate stress management [18,19]. Similar consequences might be expected in adolescents with DSPD, especially if they were expected to get up early for school and work.

In our tertiary sleep center, we noticed that not only the adolescents themselves but also the parents and other family members suffered from the consequences of the adolescent with DSPD. However, research in this field is limited, mainly addressing younger children with behavioral insomnia, showing parental insomnia symptoms, higher stress levels, decreased energy, and problems with temper and relationships for these parents [29–34]. Currently, less is known about adolescents suffering from sleep disorders and their impact on parents and other immediate family members. The limited studies available describe a negative influence of adolescent sleep problems on families, with more inter-partner conflicts and parent-child conflicts and higher levels of depression and anxiety, especially for the mothers [22–24,40]. No earlier research exists focusing specifically on adolescent DSPD and the impact of the adolescents' phase delay on their immediate surroundings.

This qualitative study focuses on the impact of adolescents' DSPD on their own and their parents' and family's daily lives and functioning. Using in-depth interviews with adolescents and their parents, we aimed to gain further insight into factors contributing to the quality of life of these adolescents and their social support system. This knowledge may be used to optimize therapy and support, but also to define patient-reported outcome measures and quality of life measurements thereby facilitating future treatment studies.

2. Method and participants

Adolescents between 12 and 18 years of age, who were undergoing treatment for circadian rhythm disorder type DSPD according to the ICSD-3 criteria [39], were included in this study. Purposive sampling was used to include both male and female adolescents spread across the age range. The exclusion criteria were: psychiatric illness of the adolescent or parents/caretakers, chronic disease or developmental delay (IQ below 70) of the adolescent and not fluent in the Dutch language. The study was conducted at the Sleep Medicine Centre Kempenhaeghe, a tertiary referral center for sleep medicine in Heeze, The Netherlands.

2.1. Medical ethics review committee

The study was approved by the Medical Ethics Review Committee Arnhem Nijmegen (approval number 2015-1756). All participants gave written consent before participating in the study.

2.2. Data collection

The first author carried out 1-h in-depth, semi-structured interviews with the adolescent and one of his or her parent(s)/caretaker(s); they were interviewed separately. The interviews took place between November 18th, 2015, and January 20th, 2016. The location was chosen according to the participants' preference: at home or the Kempenhaeghe outpatient clinic. The interview started with the open question, "What does/did it mean for you to suffer from DSPD/have a child that suffers from DSPD?". The

participants were leading, and the interviewer following the subjects they brought up and asked further questions to dig deeper into the subjective experiences of the adolescent and parents. Both the adolescent and parents/caretakers were asked about the influence of DSPD on their relationship (ie, what the adolescent thinks the impact on the parent is, and vice versa). At the end of the interview, the interviewer checked the topic list to see if all topics had been mentioned; Table 1 shows the starting topic list based upon a review of the existing literature. The interviews were recorded, and the analysis was conducted after each interview. If new topics were found during an interview, they were added to the topic list. The sample size was not determined before the start of the study, but followed the qualitative approach: after each set of interviews (one DSPD adolescent and one parent), an analysis was performed. When saturation of data occurred, two more interviews were conducted to confirm this conclusively.

2.3. Data analysis

The recorded interviews were transcribed verbatim using the software package 'Express Scribe Transcription Software for Microsoft Windows.' The transcribed text was then copied into the Microsoft Excel package. The thematic analysis started with open coding, by which each text fragment was labeled with initial open codes [27]. Subsequently, interpretive coding took place, whereby the open codes with comparable meaning were clustered into more general codes (for example, 'failing school tests' or 'getting lower grades' were clustered into 'negative effects on school results'). This process was supported with a visualization of the different themes by creating a mind-map using XMind 8 (Xmind Ltd, Hong Kong). The interpretive codes were either placed within a theme or on lines connecting themes when they expressed perceived connections (eg, "I couldn't go to school because I was so exhausted" was placed on the line between fatigue and school absence, showing their connection). After this process, five major themes were identified and described in the result section.

2.4. Quality criteria

Two researchers (KM and SP) analyzed the transcripts individually. Any disagreements between the encoded analyses were discussed. Regarding reflexivity, the interviews were carried out by a researcher with little experience in the field of sleep medicine and no children of his own (KM), who could engage the adolescents and parents with an open-minded attitude and thus decrease the influence on the interviewed subjects and questions. The thematic analysis was subsequently performed by the interviewer (KM) and a second researcher with extensive experience in the field of sleep medicine and with children of her own (SP), to take different interpretations of the transcripts into account. After analysis of the data, triangulation of the results took place by peer debriefing with three experts in the field of pediatric sleep medicine (LQ, NV, EvdH). All themes were discussed to see if these results matched with the experts' clinical experience. No additional topics were identified in this stage of the process.

3. Results

In total, 12 interviews were conducted with six adolescents and six parents, after which inclusion was stopped because of the saturation of information. Four boys were interviewed, aged 13, 15, 15, and 16, all accompanied by their mother. Two girls were interviewed, aged 12 and 17, accompanied by their mother and father, respectively. Four adolescents were diagnosed solely with DSPD (12, 15, 15, 16 years old) and received chronotherapy and light

Table 1
Topic list at the start of the interview based on previous clinical experience and the existing literature.

Topics concerning the adolescent	Topics concerning the parents
Cognitive functioning: attention span, memory	Cognitive functioning: attention, memory
School: results, studying, school absence	Work
Relationships with parents, friends, family	Relationships with child, partner, friends, family
Behavior: irritability, impulsivity	Behavior: irritability, anger
Psychological: emotional stability, mood	Psychological: stress, emotional stability, mood
Physical complaints	Physical complaints
Free time: hobbies, sports	Free time: hobbies, sports

therapy. The 13-year-old boy and 17-year-old girl suffered from both DSPD as well as chronic insomnia. All adolescents were still undergoing treatment, consisting of chronotherapy and light therapy, added by cognitive behavioral therapy for insomnia in the cases of concomitant chronic insomnia. The average interview time was 68 min.

From the thematic analysis we identified five themes: (1) Impact on adolescents: school results and social life; (2) Impact on parents: feeling guilty and powerless; (3) Impact on the family: conflicts and misunderstanding; (4) Impact on parents: being tired of everything; and (5) Factors determining or mediating the severity of impact. The themes are presented in Figs. 1–4 and Table 2 and are discussed below with illustrative quotes.

3.1. Theme 1: impact on adolescents: school and social life

All adolescents mentioned the considerable impact of their sleep problem on both their school performances and social life. Both consequences appeared to be highly interrelated, as were psychological and cognitive consequences (Fig. 1), therefore, all these items are reported in one theme.

A recurring issue was school absence due to fatigue or illness, which participants reported being the primary cause of social impact. Illustrative quotes include: “I cannot keep up with developments and changes that are experienced by my friends or

classmates. I can’t join them for activities or anything, really. When I return to school, I seem to have missed out on everything”. A parent stated: “How can he maintain friendships if he’s sick or sleeping at home all the time. I watch his social circle dwindle and see my own child become an outsider”. Participants also expressed a low motivation due to tiredness and lack of sleep, resulting in fewer social activities. “When my friends go out, I am often too tired to join, I just have no energy, especially when it gets physically demanding.” As a result, they started to feel more depressed and less cheerful in general or developed a more withdrawn personality. This led to adolescents tending to be more on their own, with a less extensive social life. Parents expressed the same concerns. A mother said: “He can just have this lifeless appearance on his face. He just can’t be motivated for anything when he is this tired”. A backlog in schoolwork also seemed to cause significant social impact. Deteriorating school results, which was said to be caused by sleepiness, concentration problems, and school absence, led to less free time. “When they go out, I’ll be at home doing schoolwork from the past few weeks.” This also led to giving up on sports or hobbies because of being too tired and physically unfit.

Consequences for social school life consisted of having fewer friends in school, bullying by classmates, working alone, and even changing schools. As a mother described: “He just couldn’t connect and blend in, so we decided to try again on a different school. A new start, you know”.

A decline in school performance was often mentioned, with reports of failing tests and dropping grades, trouble concentrating or focusing, and feeling tired or falling asleep while doing school

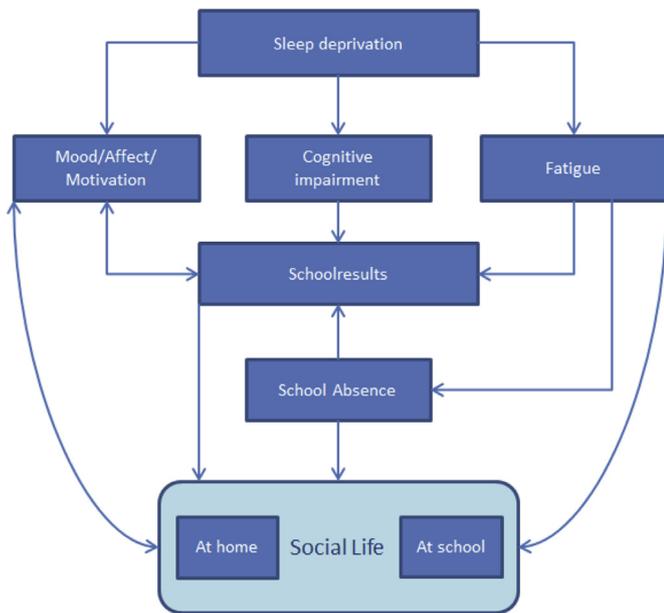


Fig. 1. Theme 1: Impact of DSPD on school and social life. The arrows represent codes from our thematic analysis showing the connections between different themes, for example: “I couldn’t go to school because I was so exhausted” is represented by the line between fatigue and school absence.

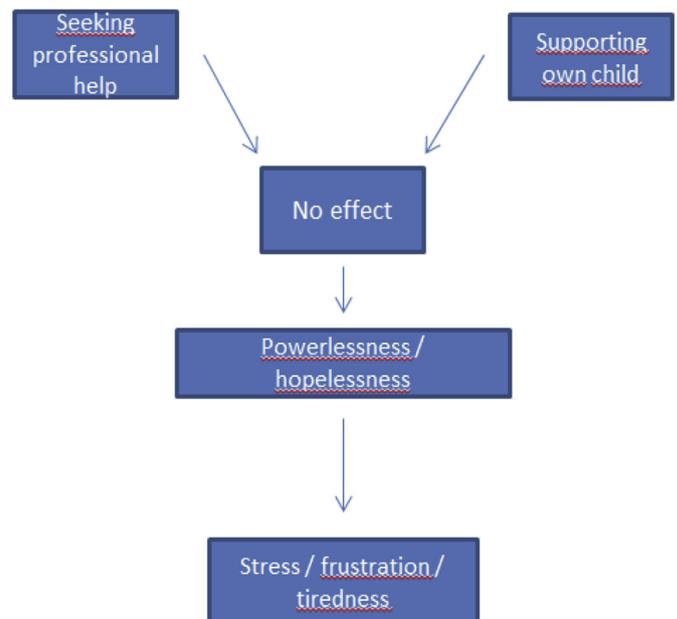


Fig. 2. Theme 2: Parents' efforts to help the child and the consequences of failure.

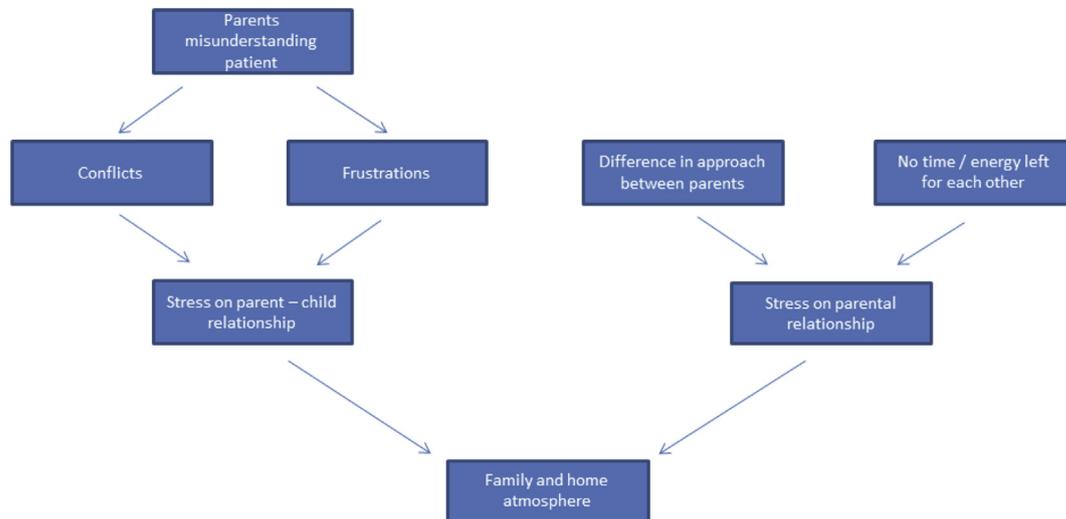


Fig. 3. Theme 3: Showing the influence on relationships and family/home atmosphere as a consequence. (the relationship between parents and child on the left side, and the relationship between parents on the right side).

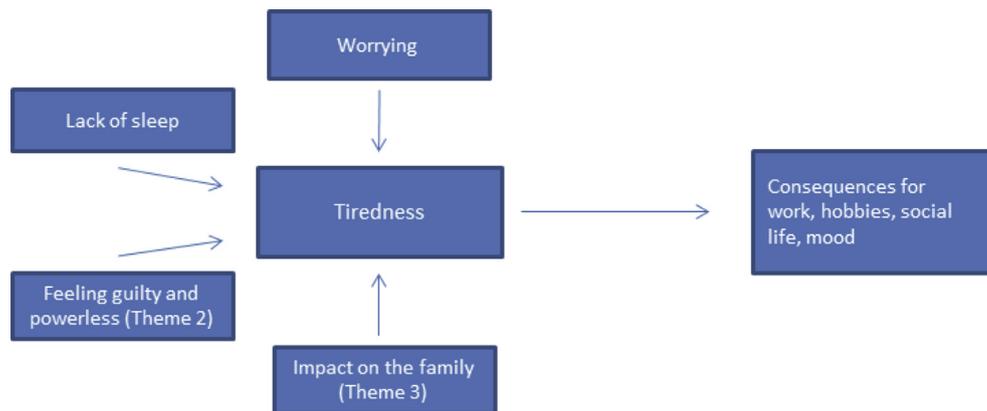


Fig. 4. Theme 4: showing factors causing parents fatigue and its consequences.

Table 2
Moderating factors.

	Deteriorating factors	Protective factors
<i>Adolescents</i>		
Personal characteristics	Always pessimistic; need lots of sleep; lazy	Always optimistic; never needed much sleep; lots of energy; smart in school; not giving in to lack of sleep
<i>School</i>		
Bad relation with teachers		Condoning bad results; allowed to sleep late; special counseling
<i>Parents</i>		
Problems adding up	Busy job; stressful lives; other family issues	
<i>Distractions</i>		
Job as a distraction		
<i>Experience</i>		
First child, not knowing what is normal		Older brother with same problem
<i>Both</i>		
<i>Understanding</i>		
A misunderstanding from work/school/friends/family results in pain, sadness, and extra burden		Understanding from school/friends/family gives support

work. This impact, however, seemed highly dependent on various mediating factors. All parents said they have had conversations with schoolteachers and deans, explaining the situation in order to make them more fully understand. This led to adolescents being allowed to stay home the first few school hours, receiving additional opportunities to retake an exam or exams were postponed, or adverse results were condoned. Another mentioned solution was to drop to a lower school level to make dealing with their sleep disorder easier. These mediating factors were said to limit school- and social impact, and are also shown in Table 2.

As shown in Fig. 1, adolescents reported that the social impact and bad school results influenced mood and affect, primarily resulting in sadness and frustration.

3.2. Theme 2: impact on the parents: feeling guilty and powerless

This incorporated subthemes relating to ‘actions to prevent/treat the sleep disorder,’ ‘supporting your child’ and ‘consequences of failure’ (see Fig. 2).

All parents stated they had undertaken extensive actions to prevent or treat their child's sleep disorder before they came to the sleep center. They had taken the child to other health care physicians, including general practitioners, pediatricians, and alternative medicine practitioners. The lack of support and understanding by many physicians bothered them. According to one: "It was hopeless. We went to the general practitioner literally five times, and each time we were sent away with nothing. She just didn't know what to do, and that cost us years of frustration." Parents reported having taken actions themselves in order to improve the situation, including stricter bedtime rules, being more strict regarding house rules, setting punishments for not going to sleep, or giving rewards for sleep-promoting behavior. Some reported imposing restrictions for their 'children's own good': "When I see his pale face and baggy eyes I won't let him go to some kind of party"; "I won't let him ride his bike alone after dark, he can't even focus on the TV." To support their child, parents mentioned staying up late along with their child. "I can't sleep when I know he can't. Not only does it make me feel guilty, but what if he needs me?"

Many parents stated that these attempts to seek treatment and support the child were insufficient. A common issue reported by parents, as well as adolescents, was the hopelessness of the situation when none of the above worked. "You just feel so powerless. Nothing works". Some parents said that they slowly give up hope for improvement. "If they told me I had to walk around in my bare buttocks to help my child, I would. But we just don't know what to do anymore. You're helpless". This feeling of hopelessness and being powerless resulted in more frustration and exhaustion for most of the parents, which is further explained in theme 4 (parents: tired of everything).

3.3. Theme 3: impact on family relationships, conflicts, and misunderstanding

This theme incorporates three groups; the relationship between parents and their child, the relationship between both parents, and the effects on the family as a whole and atmosphere at home, and their relation with each other as shown in Fig. 3.

3.3.1. Parent-child relationship

Both parents and their children reported that their relationship was affected negatively by sleep problem. In general, the consequences could be ascribed to misunderstanding towards the adolescents' behavior; thinking their child did not want to sleep instead of could not sleep was a recurrent issue. Most frustration towards the child was caused by not getting out of bed in the morning or not going to bed in the evening, the adolescent waking up parents during the night, a lazy attitude and sleeping during the day. Also, poor school results, school absence, and being forgetful and careless resulted in frustration. A mother explained: "When he is hyperactive in the evening and won't go to sleep, but I have to drag him out of bed the next morning, you eventually reach a boiling point." Another mother said: "She makes up excuses to get out of bed every night; eventually you just don't believe her anymore."

As a result of these misunderstandings, adolescents and parents both reported regularly having conflicts with each other. Most were described to be discussion-like, while some parents admitted to verbal aggression like shouting and cursing, punishing of the adolescent and emotional outbursts of anger. "At some points my hands were itching. It makes you cross your own line, I even dragged her down the stairs once and put her in the car outside because she was keeping us all awake".

One parent reported that, in a way, her mother-son relationship improved and she felt closer to her son because of the sleep

problem. "Of course it's frustrating when he wakes me up at night, but I always try to remember how hard it must be for him, losing friends and not being able to go to school. That's why I always try to be there for him, and I feel it brought us closer in a way."

3.3.2. Relationship between the parents

Parents also reported relationship issues. These mostly resulted from a difference in understanding and approach towards their child. One mother mentioned: "We are not on the same page. My husband is far more skeptical than I am, where I am trying to set rules he just does not care and puts no effort into it". Another mentioned cause leading to stress on the parents' relationship was having no time for each other: "At the end of a long day when she is finally in bed, we are just exhausted. We never go out anymore. Oh, and our sex life? Non-existent. Especially when you know she might walk in any moment". Some reported frequent conflicts with each other, in one case even resulting in a marital breakup.

3.3.3. Family and home atmosphere

The conflicts between parents and their child affected the atmosphere at home and within the family. There were references to disturbed sleep of brothers and sisters, mostly from arguments between parents and an adolescent. School mornings were reported stressful by the adolescents and parents, leading to irritation and tension for the whole family. These constant conflicts and discussions created a bad atmosphere, and one participant said: "I can't be myself at home. I'm always glad to go out, away from all these arguments".

Some participants reported feelings of sadness and grief from the impact of their problem on family relations, and also their powerlessness and incapability to change the situation.

3.4. Theme 4: impact on the parents: tired of everything

This theme revolves around parents being tired, caused by a summation of multiple factors, of which two have been described in theme 2 and 3 (see Fig. 4). It incorporates three additional sub-themes: lack of sleep, worrying, and the consequences of fatigue.

3.4.1. Lack of sleep

Not only the adolescents but also their parents reported a lack of sleep. Either from the child waking them up, or a feeling of guilt or worry for being needed, keeping them awake. Parents mentioned that this sleep deprivation resulted in frustration and cognitive consequences such as forgetfulness. A mother said: "She will make up excuses to come out of bed every night and wakes us up." Some parents also reported physical complaints following bad nights, consisting of head and back aches. Parents reported having to take naps and falling asleep on the couch or at the table, as well as having trouble to get out of bed in the morning.

3.4.2. Worrying

All parents reported worrying about their child. They were uncertain about their school and work future, worried about the social impact and their child losing friends. "He used to have so many friends; now he has become a loner. That worries me." One mother said she worried about her child's mental and physical development and his independence.

3.4.3. Consequences of fatigue

Parental fatigue had consequences at work, such as feeling tired on the job, oversleeping, inaccuracy at work, and one eventually lost a job. "An employer does not care for your problems, especially if it's 'just' your child that doesn't sleep. For them, it's nothing but a bad excuse and a whole lot of nonsense".

A commonly mentioned factor was the presence of mood fluctuations. “I feel so irritable, like my frustration tolerance is really low and I can just yell or cry over everything.” For some parents, this led to less contact with friends or family due to a lack of time, energy, or feeling unmotivated. In addition, hobbies and time for themselves were suffering.

3.5. Theme 5: factors influencing the severity of impact

During the thematic analysis and the process of creating the Mind Map, a group of interpretive codes evolved that could not be seen as a consequence of the DSPD. Instead the adolescents and their parents mentioned these items as factors influencing the severity of impact in the domains described in theme 1 to 4 (Table 2).

The most commonly mentioned factor was the amount of miscomprehension parents and adolescents received from those in their surroundings. While feeling understood from friends and school was reported as supportive, miscomprehension was said to result in frustration, mood fluctuations, tiredness, more conflicts at home, trouble at work, and a more significant social impact. A child stated “My friends don’t understand, they tell me to just go to bed early and get a good night of sleep so I don’t have to stay home from school all the time. It’s frustrating because it’s not my fault”.

Another frequently reported factor was the influence of busy jobs and daily lives, making the child’s sleep disorder just another stressful matter to handle. One parent: “If I could skip work a couple times a week, or had someone else to do the household chores, maybe I would have more time and energy to deal with her sleeping disorder. I refuse to give in on my own social life, but when friends ask me to go out in the weekend, I just want to catch up on sleep”. An adolescent said, “We also just moved house, so the friends that I still have are a long bike ride away.”

Personal characteristics influencing the impact (eg, a pessimistic or optimistic nature) were reported in all interviews, both for the parents and adolescents. Also, the family situation with or without previous experience with DSPD or insomnia mediated the impact: “She is our first child, we don’t know what’s normal behavior and what isn’t. I start seeing everything as a result of her sleep problem”.

4. Discussion

The goal of this study was to investigate the impact of DSPD on the daily lives of adolescents and their families, including social life and family relations. A qualitative approach using in-depth interviews resulted in four main themes regarding the consequences of DSPD and a fifth theme describing factors mediating the severity of impact.

While earlier research mostly focused on separate elements such as school results or mood fluctuations and depressive symptoms, also covered in this study, they did not include other important consequences such as social consequences and the influence on family life. The results of the current study provide additional insights into the overall impact of DSPD on both adolescents, parents, and the entire family as well as the relation between these consequences. Possible points of action for management, apart from interventions directly focusing on the sleep problem itself, are further discussed below.

For the adolescents themselves, school and social life seem to be the most critical items influenced by their DSPD. Sleep deprivation causes adolescents to be exhausted and not motivated enough to attend school or activities with their peers. Similar results were found in earlier studies on insomnia in adolescents [20,21].

Even though an understanding and cooperative school environment can limit the negative impact of DSPD on school results and school social life, it seems unlikely that these adverse effects can be prevented entirely. School absence and the inability to take part in social activities with peers presumably will lower adolescents’ quality of life. This is also seen in children with other chronic psychiatric or somatic disorders [25–28], in which impaired social and school function, fatigue, frustration and worrying were the main contributors to a decrease in quality of life.

As expected based on our clinical experience, both adolescents and parents report not only an impact on the functioning of the adolescent but also the parents’ and family’s daily lives. In younger children and infants with sleep disorders, earlier research has found that parents suffer from fatigue, stress, mood changes, and relational problems [29–34]. Parents of adolescents with DSPD did not mention sleep loss as the sole factor of their fatigue, but they seem to face the consequences of the managing role they take on, which seems to drain a lot of energy. Making sure the adolescent gets up and goes to school in time, and having to deal with the adolescents’ attitude, causes stress, worrying, frustration and fatigue, resulting in consequences for mood, work, family life, social life, hobbies, and the parental and parent-child relationship. These adverse effects for the parents of adolescents with DSPD have not been described before, but they are essential to acknowledge, as parents have a significant role in managing the problems of their children, including DSPD. In our experience, parents also have a crucial role in coaching their child when implementing DSPD therapeutic approaches (eg, sleep hygiene improvement and chronotherapy). Fatigue and conflicts between parents and adolescents can hamper the effectiveness of such therapeutic advice, and to optimize the chances that therapy will be useful, such effects on the parents should be taken into account.

Another result of this study is the feeling of powerlessness and hopelessness by parents caused by ineffective treatments and support attempts. In our study, these unavailable ‘resources’ were the shortage of available treatment options, recognition, and knowledge about DSPD and insomnia. Many adolescents and their parents reported having trouble receiving understanding and recognition from doctors and physicians. Most of the adolescents visited various doctors or sought help in alternative medicine before finding someone who referred them to a sleep medicine center, which shows the lack of recognition of sleep disorders among doctors. Currently, in a pediatric medicine residency, a median of only 2 h is spent on sleep medicine, whereas 23% receive no sleep medicine education at all [37]. In medical school, a mean of only 17 min is spent on pediatric sleep medicine [38]. Increasing knowledge among physicians regarding sleep, might not only help adolescents receiving faster and better treatment but with a better explanation of the cause and consequences of DSPD, it may limit the impact and stress these disorders are causing to the adolescent and his entire family.

Lack of understanding was also encountered at school, where misunderstanding from teachers towards the problem was common. Moreover, close friends, family, and colleagues often showed no sympathy, resulting in a loss of social network. Understanding and recognition from their social support system seem to be essential in mediating the severity of impact and stress experienced by the adolescents and their parents. Similar adverse effects of social unacceptance and misunderstanding on parental stress levels were found in earlier studies in children with intellectual disabilities or autism [35,36].

This misunderstanding about the cause of the sleep problem also played a common role in the parent-child relationship: instead of seeing an exhausted child that simply cannot sleep, parents often thought their child was lazy and did not want to go to sleep, leading

to frustration, conflicts, and a worse home atmosphere, with all those consequences. When sleep patterns and sleep problems are more commonly known or when better and earlier explanations about the nature of sleep problems are given to adolescents and their families, some of these consequences might be preventable.

The qualitative approach of this study made it possible to broadly explore the impact of DSPS, but also has its limitations. As with all qualitative research, subjectivity and bias in the interpretation of the interviews cannot be ruled out completely. However, we minimized this by having all interviews analyzed by at least two people with different backgrounds and triangulated with a group of sleep medicine specialists.

Only one father was interviewed compared to five mothers, and no interview had both parents present. This may have influenced insights regarding differences in parents' perspectives. Our participants were referred to a tertiary sleep medicine clinic, which might imply a rather severe DSPD. Therefore, further studies are needed to investigate if the current findings also apply to less severe DSPD.

In this study, we explored which domains of daily functioning and quality of life are affected by DSPD in adolescents. The results of this study can be used to develop further patient-related outcome measures or quality of life scales, thus permitting the amount of impact to be quantified. Given the impact of DSPD on several domains of daily functioning, it would be interesting for future studies to investigate coping mechanisms, both for dealing with this impact as well as the treatment. In addition, the relationship of DSPD symptoms, their consequences on school absence and performance, and the impact on the quality of life might be helpful to study prospectively in more detail. Furthermore, it might be worthwhile to explore whether an intervention increasing the knowledge and understanding of DSPD might increase the quality of life of these adolescents.

5. Conclusion

DSPD in adolescents not only influences their emotional and cognitive functioning but has a much broader impact that also affects their social and family life and their parents' well-being. This impact is moderated by several factors, of which support and recognition of the problem from the social system (school, work, and family members, physicians) were most often mentioned. It can be concluded that besides proper treatment of the sleep disorder itself, adolescents with DSPD and their parents can also benefit from more acknowledgment and awareness of the existence and consequences of DSPD, both by physicians as well as the general population. In turn, this can lead to more support and understanding at school, work, and family members, with a chance to limit the impact of this disorder.

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Conflict of interest

The ICMJE Uniform Disclosure Form for Potential Conflicts of Interest associated with this article can be viewed by clicking on the following link: <https://doi.org/10.1016/j.sleep.2019.05.022>.

References

- [1] Moturi S, Avis K. Assessment and treatment of common pediatric sleep disorders. *Psychiatry (Edgmont)* 2010;7:24–37.
- [2] Stores G. Aspects of sleep disorders in children and adolescents. *Dialogues Clin Neurosci* 2009;11:81–90.
- [3] Ohayon MM, Roberts RE, Zulley J, et al. Prevalence and patterns of problematic sleep among older adolescents. *J Am Acad Child Adolesc Psychiatry* 2000;39:1549–56.
- [4] Sivertsen B, Pallesen S, Stormark KM, et al. Delayed sleep phase syndrome in adolescents: prevalence and correlates in a large population based study. *BMC Public Health* 2013 December 11th;13:1163.
- [5] Ando K, Kripke DF, Ancoli-Israel S. Delayed and advanced sleep phase symptoms. *Isr J Psychiatry Relat Sci* 2002;39:11–8.
- [6] Sivertsen B, Harvey AG. Mental health problems in adolescents with delayed sleep phase: results from a large population-based study in Norway. *J Sleep Res* 2015;24:11–8.
- [7] Schmidt RE, Van der Linden M. The relations between sleep, personality, behavioral problems, and school performance in adolescents. *Sleep Med Clin* 2015 Jun;10(2):117–23.
- [8] Alfano CA, Zakem AH, Costa NM, et al. Sleep problems and their relation to cognitive factors, anxiety, and depressive symptoms in children and adolescents. *Depress Anxiety* 2009;26:503–12.
- [9] Doran SM, Van Dongen HP, Dinges DF. Sustained attention performance during sleep deprivation: evidence of state instability. *Arch Ital Biol* 2001;139:253–67.
- [10] Quach J, Hiscock H, Canterford L, et al. Outcomes of child sleep problems over the school-transition period: Australian population longitudinal study. *Pediatrics* 2009;123(5):1287–92.
- [11] Danielsson K, Markström A, Broman JE, et al. Delayed sleep phase disorder in a Swedish cohort of adolescents and young adults: prevalence and associated factors. *Chronobiol Int* 2016;33(10):1331–9.
- [12] Sivertsen B, Harvey AG. Mental health problems in adolescents with delayed sleep phase: results from a large population-based study in Norway. *J Sleep Res* 2015;24:11–8.
- [13] Baum KT, Desai A, Field J, et al. Sleep restriction worsens mood and emotion regulation in adolescents. *J Child Psychol Psychiatry* 2014;55(2):180–90.
- [14] Millman RP. Working Group on Sleepiness in Adolescents/Young Adults, AAP Committee on Adolescence. Excessive sleepiness in adolescents and young adults: causes, consequences, and treatment strategies. *Pediatrics* 2005;115(6):1774–86.
- [15] Gangwisch JE, Babiss LA, Malaspina D, et al. Earlier parental set bedtimes as a protective factor against depression and suicidal ideation. *Sleep* 2010;33(1):97–106.
- [16] Gromov I, Gromov D. Sleep and substance use and abuse in adolescents. *Child Adolesc Psychiatr Clin N Am* 2009;18:929–46.
- [17] Hysing M, Sivertsen B, Stormark KM, et al. Sleep problems and self-harm in adolescence. *Br J Psychiatry* 2015;207:306–12. <https://doi.org/10.1192/bjp.bp.114.146514>.
- [18] Chen M, Wang EK, Jeng Y. Adequate sleep among adolescents is positively associated with health status and health-related behaviors. *BMC Public Health* 2006;6:e59.
- [19] Shochat T, Cohen-Zion M, Tzischinsky O. Functional consequences of inadequate sleep in adolescents: a systematic review. *Sleep Med Rev* 2014;18:75–87.
- [20] Roberts RE, Roberts CR, Chen IG. Impact of insomnia on future functioning of adolescents. *J Psychosom Res* 2002;53:561–9.
- [21] Roberts Robert E, Roberts Catherine R, Chen Irene G. Functioning of adolescents with symptoms of disturbed sleep. *J Youth Adolesc* 2001;30(No. 1).
- [22] El-Sheikh M, Kelly RJ, Bagley EJ, et al. Parental depressive symptoms and children's sleep: the role of family conflict. *J Child Psychol Psychiatry* 2012;53(7):806–14.
- [23] El-Sheikh M, Tu KM, Erath SA, et al. Family stress and adolescents' cognitive functioning: sleep as a protective factor. *J Fam Psychol* 2014;28(6):887–96.
- [24] Kalak N, Gerber M, Kirov R, et al. The relation of objective sleep patterns, depressive symptoms, and sleep disturbances in adolescent children and their parents: a sleep-EEG study with 47 families. *J Psych Res* 2012;46(10):1374–82.
- [25] Bastiaansen D, Koot HM, Ferdinand RF, et al. Quality of life in children with psychiatric disorders: self-, parent, and clinician report. *J Am Acad Child Adolesc Psychiatry* 2004;43:221–30.
- [26] Watson SMR, Keith KD. Comparing the quality of life of school-age children with and without disabilities. *Ment Retard* 2002;40:304–31.
- [27] Telman LG, van Steensel FJ, Maric M, et al. Are anxiety disorders in children and adolescents less impairing than ADHD and autism spectrum disorders? Associations with child quality of life and parental stress and psychopathology. *Child Psychiatry Hum Dev* 2017;48:891–902. <https://doi.org/10.1007/s10578-017-0712-5>.
- [28] Varni JW, Limbers CA, Burwinkle TM. Impaired health-related quality of life in children and adolescents with chronic condition: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the Peds QLTM 4.0 Generic Core Scale. *Health Qual Life Outcomes* 2007;5:43.
- [29] Lam P, Hiscock H, Wake M. Outcomes of infant sleep problems: a longitudinal study of sleep, behavior, and maternal well-being. *Pediatrics* 2003;111:e203.

- [30] Byars KC, Yeomans-Maldonado G, Noll JG. Parental functioning and pediatric sleep disturbance: an examination of factors associated with parenting stress in children clinically referred for evaluation of insomnia. *Sleep Med* 2011;12: 898–905.
- [31] Eckerberg B. Treatment of sleep problems in families with young children: effects of treatment on family well-being. *Acta Paediatr* 2004;93:126–34.
- [32] Hiscock H, Wake M. Infant sleep problems and postnatal depression: a community-based study. *Pediatrics* 2001;107:1317.
- [33] Martin J, Hiscock H, Hardy P, et al. Adverse associations of infant and child sleep problems and parent health: an Australian population study. *Pediatrics* 2007;119:947.
- [34] Bayer JK, Hiscock H, Hampton A, et al. Sleep problems in young infants and maternal mental and physical health. *J Paediatr Child Health* 2007;43:66–73.
- [35] Saloviita T, Italinna M, Leinonen E. Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX model. *J Intellect Disabil Res* 2003;47:300–12.
- [36] Gray DE, Holden WJ. Psycho-social well-being among the parents of children with autism, Australia and New Zealand. *J Dev Disabil* 1992;18:83–93.
- [37] Mindell JA. Sleep education in pediatric residency programs: a cross-cultural look. *BMC Res Notes* 2013;6:130.
- [38] Mindell JA. Sleep education in medical school curriculum: a glimpse across countries. *Sleep Med* 2011 Oct;12(9):928–31.
- [39] American Academy of Sleep Medicine. International classification of sleep disorders. In: American academy of sleep medicine, Darien, IL. 3rd ed. 2014.
- [40] Brand S, Gerber M, Hatzinger M, et al. Evidence for similarities between adolescents and parents in sleep patterns. *Sleep Med* 2009;10(10):1124–31.