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Psychosocial Challenges Related to Delayed Sleep Phase Disorder

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Abstract: Delayed sleep phase disorder (DSPD) is a disorder where the circadian rhythm is delayed according to the conventional norms, often resulting in school- and work related difficulties as well as emotional challenges. Research on the experiences of having DSPD is lacking, and to enhance our understanding we conducted a qualitative study using in-depth semi structured interviews focusing on the challenges of having DSPD. A sample of 9 participants (16-23 years) diagnosed with DSPD was interviewed and analysis was done using systematic text condensation. A core theme in all interviews was how to cope with different challenges related to the disorder. We labelled the identified challenges: 1) To give something up; 2) To blame something or someone and 3) To have a problem or not. Awareness of these challenges adds to our understanding of the daily struggles of those with DSPD and may improve clinicians` competence and ability to help them.

Keywords: Delayed sleep phase disorder, adolescents, young adults, sleep, systematic text condensation.

INTRODUCTION

Delayed sleep phase disorder (DSPD) is probably the most common circadian rhythm sleep disorder [1]. The symptoms consist of major difficulties falling asleep and problems awakening at a socially acceptable time. As a consequence, people who have DSPD often experience work and school related impairments [1]. DSPD is most common among adolescents and young adults and the prevalence is between 5% and 16% according to the International Classification of Sleep Disorders (ICSD-2), and in accordance with a recent review and a recent prevalence study [1-3]. DSPD has been shown to have high co-morbidity with other conditions such as depression, anxiety and attention disorders [4, 5]. There are various hypotheses concerning the pathophysiology of DSPD based on biological and psychosocial factors [6-8], however the aetiology is still mainly unknown [9].

Professionals might often misdiagnose people who have DSPD with sleep-onset insomnia (and unsuccessfully treat them with sleeping pills) if proper examination is not performed [10]. According to ICSD-2, ten percent of people with chronic insomnia in sleep clinics suffer from DSPD [1]. Research on DSPD has primarily focused on sleep and the underlying circadian rhythm. Thus knowledge about how DSPD might affect self-image and perceived interpersonal relationships is lacking.

DSPD is recognized among researchers to be a bio-psychosocial disorder. However, parents, psychologists, doctors and teachers might believe that the adolescent or young adults` sleep-wake problems and difficulties at school or work are motivational or behavioural in nature [10]. This conception of the problem might eventually be adopted by the young person and add to the problems innate in the diagnosis [10]. To understand why many with DSPD do not comply with recommended treatment options and drop out of treatment studies [9, 11], we need to know more about how they perceive their daily lives and their options for change. Qualitative methods allow us to gain new information from the patient perspective, which provide an opportunity to develop new descriptions and new ideas about the group of informants in question.

We set up a qualitative study to enhance our understanding of DSPD, especially in terms of daily challenges and coping strategies. The aim was to develop a phenomenological understanding and description of the informants` experiences of having DSPD [12].

METHODOLOGY

We conducted a qualitative study using in-depth semi structured interviews focusing on the challenges associated with having DSPD. It is important to reflect over how the researcher's preconceptions might influence the research results [13]. Before conducting the interviews, two members

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Table 1. Demographic and Overall Psychological Information for Each Informant

I	Sex	Age	School Situation	Living Situation	Grades	MEQ	HADS Anxiety	HADS Depression	DLMO	Mid Sleep	Attention Clinical/NonC
1	Female	18	High school	Lives with both parents	4.0	Definitely evening type	4	3	23:12	06:03	50.0/50.0
2	Female	17	High school	Lives with both parents	4.4	Moderately evening type	13	2	23:12	03:29	27.7/72.3
3	Female	16	High school	Lives alone	4.3	Moderately evening type	5	2	20:55	04:28	45.1/54.9
4	Female	16	High school	Parents have joint custody	3.8	Moderately evening type	10	3	01:00*	04:45	99.9/0.1
5	Male	17	High school	Lives with both parents	4.8	Moderately evening type	4	9	00:00*	06:00	42.9/57.1
6	Male	17	High school	Lives with both parents	4.9	Definitely evening type	2	1	23:26	07:01	50.0/50.0
7	Male	21	University/ College	Several room-mates	4.5	Definitely evening type	7	4	02:00*	08:34	27.1/72.9
8	Male	23	University/ College	Several room-mates	4.5	Moderately evening type	4	6	23:10	05:47	54.1/45.9
9	Female	19	University/ College	Lives with boyfriend	5	-	-	-	-	-	-

I=Informant, Grades=Self-reported average school grade (1-6, 6 being top grade), MEQ=Horne-Ôstberg Morningness-Eveningness Questionnaire, HADS=Hospital Anxiety and Depression Scale, DLMO=Dim Light Melatonin Onset, Mid sleep=the middle time point of sleep onset and sleep offset and Attention Clinical/NonC=Clinical or Non-Clinical confidence index associated with ADHD assessment on Conner`s Continuous Performance Test II (CPT-II).
*In some cases the informants went to bed before the melatonin level reached 4 pg/ml, the time given in the table is the time of the last sample before going to bed.

of the research group experienced in working with people with DSPD (co-authors BB and SP) noted what they predicted would be the answers to the questions in the interview guide. This represents a basis for reflecting about whether the information we gained through the study provided new insight, or whether we merely confirmed our preconceptions [13]. The co-authors expected the participants to say that it is tiring not to be able to fall asleep; that it is a problem for themselves, their parents and their teachers; that they become tired and unfocused from sleep loss; that it has consequences for their schooling and education and that it can become a problem later when they look for a job. They also predicted that participants would have tried, with limited success, to advance their delayed sleep phase by going to bed earlier and getting up early for school or studies.

Study Setting

The study took place at the sleep laboratory at the Faculty of Psychology at the University of Bergen,Norway. All informants had signed up for a randomized controlled trial (RCT) on the treatment effects of bright light therapy and melatonin (data not yet published). During the first meeting participants were asked if they would participate in an interview about how they experienced their sleep pattern.

Participants

Informants were recruited from the participants with DSPD included in the RCT partly based on convenience (six informants were selected on convenience; they were enrolled in the qualitative study in parallel with their order of enrolment in the RCT) and partly on critical case sampling (three informants were selected based on possession of good reflexivity and verbal proficiency during the first meeting) according to Patton's purposeful qualitative sampling categories [14]. Six high school students (4 women, 2 men) and four university/college students (2 women, 2 men) aged 16-23 years (mean age=18.2, SD=2.4) were interviewed. One interview (woman, university/college student, age 23) was lost because of tape failure, leaving nine transcripts for analysis.

All participants were diagnosed with DSPD based on the diagnostic criteria of the ICSD-2 [1] and they had been screened for sleep disorders other than DSPD, moderate to severe psychopathology (assessed with SCID-I screening interview [15], somatic disorders or conditions assumed to affect sleep (i.e. migraine, B12 deficiency), serious somatic disorders (i.e. rheumatoid arthritis, diabetes), medications or treatments assumed to affect sleep (i.e. sedative anti-histamines, antidepressants, hypnotics), substance abuse or night work. No participants had IQ < 70 and none were breast feeding or pregnant.

Further background information such as demography and an overall psychological description of each participant is presented in Table **1**. The measures included are: I) self-reported average grade point. The range is 1-6, where 6 is the best possible grade; II) the Hospital Anxiety and Depression Scale (HADS), which provides a score for anxiety and for depression, scores range from 0-21 on each scale and ≥8 is considered elevated score above what is expected in a normal population [16]; III) the Morningness-Eveningness Questionnaire (MEQ), consists of 19 items related to time of day preferences for physical and mental activities, as well as judgments of subjective alertness after rising and before bedtime. Scores range from 16-86 (the categories are definitely evening type, moderately evening type,

intermediate type, moderately morning type and definitely morning type) [17]; IV) Dim light melatonin onset (DLMO) is the time in which the saliva melatonin level has raised above 4 pg/ml in saliva. We used a validated DLMO protocol [18]; V) Mid point of sleep, which is the average middle time point between sleep onset and sleep offset retrieved from a week of sleep diary from each participant; and VI) the confidence index associated with ADHD assessment on the Conner`s continuous performance test (CPT-II). This index gives an indication of the chances out of 100 that no significant attention problem exists [19]. The CPT-II was administered between 1 and 2 p.m. during a daytime functioning protocol as a part of the RCT.

Ethics

The participants signed a consent form prior to participation in the qualitative study. For informants under 18 years of age, parents also signed the consent form. All participants were informed that participation in the study was voluntary, and that they were free to withdraw from the study at any time without any consequences. Approval was obtained from the Regional Committee for Medical Research Ethics in Western Norway and the Norwegian Data Inspectorate.

Data Collection

In-depth semi structured individual interviews were conducted by the first author from October 2008 until November 2010. The interviews lasted 25-59 minutes (mean length=39.1 minutes, SD=10.5). The interview guide was developed on the basis of knowledge from existing research on DSPD and from BB and SP's clinical work with people who have DSPD. All authors of this article contributed to the development of the interview guide; four psychologists (AWL, ID, SP & IHN), one medical doctor (BB) and one physiologist (IWS). The main themes in the interview guide were: development of the sleep pattern, beliefs about the origin of the sleep pattern, attempts to cope with the sleep pattern, consequences of the sleep pattern, thoughts about the future, and self-image.

Questions asked during the interviews were, for example: "How would you describe your sleep?", "Can you tell me about a specific situation when your sleep pattern had consequences for you?" and "Has your sleep pattern in any way affected the way you look at yourself?" The wording in the interview guide was developed based on Kvale's [20] recommendations for beginning with open questions to gain insight into the informants` life world, and then using a funnelling approach where more specific questions were asked. During the interviews, the interviewer sought to check her understanding by reflecting back to the informant what she had heard, and asking for descriptions of specific situations as opposed to general perceptions, also in line with recommendations by Kvale [20]. All interviews were audio taped (using a Sony Digital Recorder ICD-SX57) and transcribed verbatim by the first author.

Analysis

We used editing analysis style, where categories were developed from the empirical data rather than using a template analysis style, which is theory driven from predefined theoretical concepts [21]. When all interviews were conducted, we followed the standard four steps of systematic text condensation [12, 22]. Systematic text condensation as described by Malterud [22] is inspired by Giorgis phenomenological analysis and has many similarities with the procedures of grounded theory [12, 22, 23]. This approach is well suited for development of new concepts in a transverse analysis where information from different informants is being summarized.

We followed these four stages of analysis: review the whole text to identify themes, code units of meaning, abstract the meaning and finally summarize the content within the coded groups to generalized descriptions and concepts. The first and second authors have training in a range of different qualitative analysis approaches as a part of their education. The first author has practical experience in using systematic text condensation. The second author has practical experience in using a modified grounded theory approach [24, 25] and theoretical knowledge of systematic text condensation.

The first and second author initially developed suggestions for codes by separately reading all transcripts and discussing the emerging themes (stage one). Agreement between the coders was not sought after; we rather tried to expand possible ways of understanding the interviews. On the basis of these discussions, the first author systematically coded the units of meaning in the transcripts (stage two). Then the first author met several times with the rest of the research team to discuss the emerging codes on the basis of selected parts of the transcribed interviews. These discussions functioned as an audit where overlapping of codes and the structure of the categories were challenged and discussed. These discussions also informed the first author in the next step, which was to abstract the meaning from the codes that seemed to cluster together thematically (stage three). Through further discussions, we decided on core categories which summarized the range of themes (stage four). Although full saturation can probably never be achieved, by the ninth interview very few new codes were being developed, no new main issues emerged and we therefore ended the data collection at this point. The analysis was assisted by the NVivo 8 program.

RESULTS

According to our preconceptions, informants talked about how difficult it is to fall asleep at night and to get up in the morning and how this affects school performance and study behaviour. Their sleeping patterns often led to conflicts with family and friends. For example, one informant described how her family reacted with exasperation when she delayed an important family trip because of oversleeping. Others described how parents would protest against the informants' habits of doing chores, schoolwork or recreational activities in the bedroom at night rather than going to sleep. The informants reported that common emotional reactions from others would be irritation, exasperation and amusement on their behalf (such as making fun of them). Informants also talked about how they thought their sleep pattern might create problems in a future work situation and that they had tried to go to bed earlier and get up early for longer periods of time, without being able to adjust their sleep rhythm.

When we analysed the transcripts, three main themes emerged from the informants` descriptions of patterns of thoughts, behaviours and feelings that were not part of our preconceptions. We coined these three themes or categories specific challenges: "To give something up", "To blame something or someone" and "To have a problem or not" Quotations illustrating the findings are presented in the text.

Challenge 1) To Give Something Up

Having DSPD was described as having to give something up (i.e. sleep, school, time to do school work, social activities and an image of being a responsible individual).To follow society's sleep-wake pattern implied getting up early and losing sleep. The informants could not choose when to actually fall asleep, but they could choose when to go to bed and when to get up (by setting an alarm clock or being woken up by others). Over time, to get up early led to extreme tiredness because they did not get enough sleep. This is one informants` description of how she felt about being tired at school:

Participant (P): It, like when it comes to school and stuff like that, it's not very enjoyable [for me] to, kind of, sit there, and really want to pay attention, I mean I really want to pay attention but my eyes just cannot stay open, even if I am trying.

Going to bed at a socially acceptable time represented giving something up as well, because this time was special for these informants as it was the time during the day when they felt awake. Thus, giving up this time meant giving up the single time during the day when they were alert, energetic and eager to be awake. This was a time when they could catch up on school work, and do the things they would be too tired to do in the mornings and during school time.

Alternatively, following one's own sleep rhythm meant giving up time with others. In the mornings, getting up late meant missing classes, lectures and sometimes pleasurable activities. In the night time, shops and recreational places were closed and friends were asleep. The social aspect of being a student was then easily lost, as described by a male college/university student: "I do sort of, of course make good use of my day because I stay up longer, but then everything else is closed and shut and sleeping, you know?"

This challenge of either following one's own sleep phase or try to follow the rhythm of society seemed to have consequences for the informants' self-image. Not getting up in the morning or not going to bed at a socially acceptable time meant giving up a conception of oneself as a responsible individual. This behaviour increased the chances of interpersonal conflicts and self-blames (i.e. "you are late for school – again!"), here described by a female high school student: "Yes, because at school and stuff, I feel that everybody perceives me as this slacker, because nobody, yes, she is always late and things like that, right?"

Informants seemed to more or less consciously vary about which "solution" to this challenge they chose, depending on the consequences in each specific instance. For example, if they had an exam, it would naturally be more desirable to give up sleep than to miss out on the exam. However, it could be more desirable to get enough sleep when nothing important is planned the next morning. Also, sometimes the informants would sleep through alarm clocks and be late for school without it being a conscious choice. This represented a difficult challenge for them, as some of the informants said that they did not quite identify with being late (or being a "slacker") and going to bed at a socially acceptable time did not help them overcome this challenge.

Challenge 2) To Blame Something or Someone

This challenge consisted mainly of the informants' descriptions of blaming themselves for their sleeping pattern or blaming society and/or biology. Each of these understandings signified undesirable outcomes for them. Blaming themselves might seem like taking responsibility, but it also implied being at fault. Taking responsibility for their sleeping pattern implicitly gave permission to those around them to expect them to do something, to change and to try to find a solution, which the informants might be unable to do. Blaming themselves could also lead to being labelled lazy, ignorant and a slacker. Several informants described themselves as being lazy, here exemplified by a male high school student:

Participant (P): Well I, I know that I am generally lazy.

Interviewer (I): Okay, so you, yes. [laughs]

P: [laughs] Yes, they know that, my parents too.

(. . .)

P: It is of course a little tough [to handle], but that is just the way it is.

The second "solution" to this challenge could be to blame others, or society, for their delayed sleep phase. Some informants suggested that if things had been different and "everything" (school, work and so forth) had not started so early in the morning, their sleep pattern would not be a problem, and then there would be nothing to blame them for. Alternatively, blaming others meant risking conflicts with others and being looked upon as not accepting responsibility for their own "disturbed" sleeping pattern. One informant explained that society's rhythm was the reason she dreaded the mornings and was tired throughout the day when there were expectations for her to meet:

Participant (P): If I could sleep until noon every day then that would be okay by me, because when I can sleep until late, I am usually rested.

Interviewer (I): Yes.

P: And have lots of energy and want to do things. But when I have to get up at six, seven, eight o'clock, then it is more like ah! It is really just a hassle.

(. . .)

P: Yes, it demands quite a bit of you, and it demands that you are awake and clear when all things start, as one might say, in the morning.

I: Yes.

P: But, if I didn't have that pressure upon me [to get up] and knew I could sleep in the next day and, then I think it would have worked.

The third alternative in terms of whom or what the informants blamed for their delayed sleep pattern, was

biology ("maybe this is just who I am?"). Several informants went back and forth in the same interview between seeing the sleep phase delay as their own fault and blaming biology for it. In the first quotation below, this participant explains how it irritates him that people do not understand what it is like for him to have this sleep phase delay:

Participant (P): Yes, most people I talk to about it say "can you not just go to bed early?"

(. . .)

P: Well I have tried to say that it is not that simple and stuff, but, people maybe just don't understand it.

Interviewer (I): No. How do you feel when they say that? How do you react to that?

P: I get a bit irritated.

Later in the interview:

P: Ehm, I am not quite sure, I am, have sometimes thought that like I said before that I, if I had tried harder then maybe I would have made it.

I: Mhm.

P: So, in that sense I guess I do look at myself as a little, a little lazy.

Challenge 3) To have a Problem or Not

The third challenge was described as whether to define the delayed sleep phase as a problem or not (while most informants talked about their sleep pattern as a problem, two high school boys consistently denied it being a problem for them during the interviews). One female high school student described fighting with her parents about the question of blame, making her sleep pattern a problem and a reason for conflict: "Ehm, okay, my parents and I have fought a lot, because they say `it is your own fault, you don't bother to go to bed at night, and therefore you cannot get up in the morning."

Many informants clearly expressed that the delayed sleep phase was a problem for them, sharing the view of their parents and friends. Frequently being too late for appointments, informants would naturally develop the habit of excusing themselves for being late. If the informants got out of bed early and endured the extreme sleepiness that followed, they would excuse themselves for being sleepy. Some informants described that excuses were often accepted, but also that they tried to compensate by, for example, smiling and appearing happy even though they were extremely tired.

Having a problem also means you are expected to try to solve it. The need for change might be problematic if the informant did not know how to bring about this change. Several informants said they had tried very hard to bring about change in their sleeping pattern, without success. One participant described it in the following manner:

Participant (P): But it turns out that for me, even if I am pulled out of bed in the morning by my girlfriend, and she also makes sure I go to bed at a reasonable hour and over time, I am still just as tired every morning.

(. . .)

Interviewer (I): Yes, you have tried, yes. But it doesn't work the way you thought?

P: No, it doesn't become easier to get up. For example it is easier to get up after eight hours of sleep than three or four, but it is not like I wake up and feel rested. You still need to be asked several times and pulled out of bed.

Accepting the fact that a change is needed, and still being unable to change can take a great toll on the informants' self-efficacy [26]. There seems to be a bit of hopelessness in the situation for many of the informants; a few of them also said that they sometimes felt like giving up, here described by a female high school student:

Interviewer (I): Yes, mhm. Do you look at your sleep pattern as a burden?

Participant (P): Yes, it is, it affects me a lot psychologically sort of, it is like, if I go to bed now then I cannot sleep, then I might as well be awake. And then that results in problems the rest of the day and then, I maybe become grumpy and then, yes.

I: Yes because, when you say it affects you a lot psychologically, what do you mean by that?

P: I don`t really know, I just know that there is something in me in a way, I know that it won't work and then, I sort of just give up.

Another "solution" to this challenge might be to define the delayed sleep phase as not being a problem. Two young informants (both male high school students) denied through the whole interview that their delayed sleep phase was a problem, stating, for example: "It doesn't bother me." This is in spite of the fact that they sought help for their sleep phase delay by signing up for a treatment study for DSPD. From those two interviews, it seemed that there might be several perceived advantages in not seeing the delayed sleep phase as a problem, at least in the short term. First, the pressure to change is most likely reduced as a result of not admitting to have a problem. Second, not admitting to have a problem may in the short run make life seem less complicated. Third, not attempting to change the sleep phase may protect the person from experiencing him- or herself as failing. Consequently, when these two informants did not define their sleeping pattern as problematic, it might have protected them against several potentially troubling feelings.

Relationships Between the Specific Challenges, Interpersonal Conflicts and Self-Image

Several of the informants` descriptions of their reactions and of others' reactions suggested that frustration and conflicts arose around their behaviour, in relation to teachers, parents, siblings and friends. The interviews suggested that this was likely to happen regardless of which of the "solutions" to the challenges the young people "chose". For example, with regard to challenge 1), an inability to follow society's sleeping pattern clearly led to frustration and conflicts with teachers and parents. One participant described how sleeping late led to conflicts with his father, who would have liked a hand with household chores during the daytime when his son was sleeping.

Informants vividly described how the opposite solution to challenge 1), namely to go to bed early and get up early,

caused them to be too drowsy until mid-day to be able to concentrate or to follow up on obligations at school. In addition, we came to believe that blaming society (challenge 2), and diminishing the problem (challenge 3), might be a source of frustration and interpersonal conflict. For example, one informant described how he resented his mother's repeated insistence that he had to go to sleep earlier to be able to get up earlier, stating that he did not "see it as a problem". A few informants fluctuated between a feeling of righteousness ("I'm not to blame") and a sense of being "just a lazy slacker", perhaps because they did not know what to think about themselves. Because this wavering between avoiding and accepting blame probably sometimes was enacted in interactions with parents and friends, we believe this might be a source of conflict.

DISCUSSION

By interviewing adolescents and young adults about their experiences of having DSPD, we found that their descriptions were partly in line with our preconceptions. However, the informants also described their experiences with DSPD as something we framed as three main specific challenges; "To give something up", "To blame something or someone" and "To have a problem or not".

We find it intriguing that many informants described these challenges as if there was no apparent solution. In that respect, the challenges appeared to be dilemmas, defined as "a choice between equally undesirable alternatives" [27]. There seemed to be something desirable and undesirable to either possible solution to all the challenges. Whether the informants made a conscious "choice" of one solution rather than another is unclear and seemed to vary both regarding circumstance and within and between the different informants. For example, challenge 1) about what to give up had implications for how the informants were perceived by others and their self-image, either as a person who is on time in the mornings but extremely tired (if they followed societies' sleeping pattern), or as a person who did not care (if they did not follow societies sleeping patterns, which could, on the other hand, give them enough sleep). Parents, friends and teachers seemed to not be aware of what the informants actually had to give up (or choose between) when they went to bed at socially acceptable times: a time during their wakeful period when they were eager to be awake, to catch up on school work, and do the things they would be too tired to do in the mornings and during school time.

The challenge of blaming something or someone (challenge 2) was described by the informants as having personal and social consequences (and consequences for self-image). We reckoned that if the informants themselves were convinced that biology was to blame, and/or they blamed society, they could feel less guilty. However that would also mean that they would feel in less control of their situation. Another aspect of their blaming biology or society is that they risked being blamed for not accepting responsibility for their behaviour by those of their relatives, teachers and friends who perceived their motivation and behaviour as a cause of the sleep pattern. This challenge resembles a dilemma in our opinion. Also, the challenge of defining or not defining one's sleeping pattern as a problem (challenge 3) had social implications and implications for self-image; both defining and not defining one's delayed sleep phase as a problem had favourable and unfavourable elements. Defining their sleep pattern as a problem might bring the informants in sync with what others think, and he or she might receive understanding and sympathy. However, it might have implications for the participants` self-image, as others might define the problem as his or her fault, and the informant might internalize others` opinion of them as being irresponsible, perhaps lazy. This is in line with Dagan's hypothesis that comments and conflicts with others add to the problems innate in the diagnosis [10]. It seemed that there might be several advantages in *not* regarding the delayed sleep phase as a problem (which is a bit counterintuitive), at least in the short term. This finding was a surprise to us, and it also made us think of challenge 3 as a dilemma.

We find it interesting that the young adults with DSPD seemed to describe an enhancement of their energy levels as they came closer to their bed-times. This is in contrast to most people with a normal sleep phase, who often become increasingly sleepy as the bed-time approaches. However, this may be a phenomenon related to the diurnal preference towards eveningness [28].

Strengths and Limitations of the Study

In-depth interviews with informants whose voices are seldom heard in research on DSPD represent an obvious strength. A limitation is that we did not secure informants' feedback on our interpretations of their interviews after the analyses were completed. Second, there probably exist challenges that we did not discover, so that additional interviews with other informants might have been useful. Third, informants were not followed over time. They might develop solutions to their challenges as they mature and adapt to new situations. Many informants stated (although they had been told that they were diagnosed with DSPD on inclusion) that they still did not know if they had DSPD and that they had never thought about their sleep pattern as an illness or diagnosis before. They might not yet have had the time to "make up their minds" about how to perceive their delayed sleep phase disorder shortly after being informed about the diagnosis.

Interviewing other teenagers and young adults who do not have DSPD, using the same questions, might shed light on whether these challenges are restricted to young people with DSPD, or whether they might represent general challenges in young people or in people with other disorders. Furthermore, the interviews might have turned out differently with another interviewer. Richards and Emslie [29] suggest that who respondents think you are, affects what you are told by them. The interviewer was a thirty-year-old female psychologist trained in communication on sensitive issues. She was also involved as an administrator in the RCT the informants were about to take part in for treatment of DSPD. Informants might have expected the interviewer as being particularly interested in problems associated with having DSPD and in helping them to change. However, the informants also mentioned positive aspects of staying up late, and two informants clearly stated that DSPD did not represent a great problem for them, indicating that informants did not only focus on the problematic aspects of having DSPD in the interviews.

Another possible limitation of this study is that some of the symptoms, problems and challenges the informants described, might be attributed to symptoms of co-morbid disorders [4, 5]. Also, circadian misalignment is commonly associated with for example mood disorders and attention disorders [30]. However, all informants underwent thorough screening before inclusion and none had previously been diagnosed with mood- or attention disorders. Table **1** gives an overview of relevant measures and most of these informants do not seem to suffer from co-morbid mood and/or attention disorders. The elevated scores on anxiety (informant 2 and 4), depression (informant 5) and attention deficit (informant 4) that might be indications of co-morbid disorders, may just as likely be symptoms of sleep deprivation and drowsiness (Table **1**) [31].

Transferability

This article is based on a highly selected sample of youth, all of whom were interested in gaining information, contributing to research and possibly receiving help for DSPD. They might represent a group of people with DSPD that are on average more attentive to their sleeping problems, and on average more motivated to make changes. In this respect they can be expected to be similar to patients we see in clinical settings. The informants in this study were also relatively well-functioning young adults with DSPD. They were all enrolled in high school or college/university and most had better than average school grades (Table **1**). Young adults with DSPD who have a more severe phase delay, who have dropped out of school and have problems maintaining a normal life, might experience different, and more, challenges than our informants. Hence, the results presented above might not be transferable to young people who are less attentive to their sleeping pattern, who have a more severe phase delay and to those who do not wish to make changes, such as, for example, young people who are brought to specialists because of their parent's wishes.

Clinical Implications

We believe that the challenges described above may have several clinical implications and that the results described in this article might lead to a better tailoring of treatment interventions for DSPD. First, the interviews importantly remind us that change is not easy. Second, receiving a diagnosis and an explanation of DSPD may reduce the challenge of whether to blame oneself or others, because a mainly biological explanation may take blame away from the person. Third, adequate treatment [32] might eliminate the challenge of whether to sleep late and get enough sleep or get up early.

Respecting the choice of some young people to avoid defining the sleep phase as problematic might be a relevant alternative for professionals. Not defining the sleep phase as problematic and not trying to change it at the time might allow the young people to preserve their sense of self-efficacy at a time in their lives when they might need to feel in control. Paradoxically, allowing the youth with DSPD the freedom not to change can possibly increase the chances that they might seek help for their sleep phase at a later time when circumstances are more favourable and when they feel ready. Also, some people might be able to regulate their lives without changing their DSPD, finding ways out of these challenges, such as, for example, working night shifts.

Developing a healthy self-image and identity as well as interpersonal relationships (as the informants navigate transitions from family of origin towards stronger reliance on peer relations and romantic relationships) is a main task during teen years and young adulthood [33]. A healthy sense of self regard and good interpersonal relations may increase resilience against, for example, depression and other problems [33]. The study suggests that professionals working with DSPD in youth might choose to include in their work a mapping of each patient's challenges. Such discussions might help young patients to realize that many of their reactions are normal and that their experienced challenges are understandable. This may also strengthen the treatment alliance between doctor and patient. This study indicates that young people with DSPD might be searching for a way of living their everyday lives while maintaining their self-respect in addition to minimize the interpersonal consequences their sleep pattern potentially might have.

CONCLUSION

The results we have presented contribute to filling an important gap in our understanding of the challenges faced by people who have DSPD. This study is one step along the way of discovering and describing a range of challenges that might be associated with DSPD. Knowledge about some of these challenges, and knowing how to look for even more challenges, might change the way we approach these young people as researchers and clinicians. We suggest that caregivers (psychologists, parents, doctors, nurses and others) might be in a better position to help and support young people with DSPD if they recognize some of the challenges this diagnosis entails. We also suggest that awareness about these challenges should be acknowledged in future research on DSPD and our approach might be a step in the direction of explaining why many young people with DSPD are considered as "non-compliant" to treatment. This might increase our understanding of the perceived losses and gains of trying to adapt to the socially accepted sleeping patterns and other challenges faced by youngsters suffering from DSPD, which can influence the emotional consequences of the disorder.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflicts of interest.

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