Swedish Internet forum users’ views and experiences of melatonin treatments for troubled sleep

Siri Jakobsson Støre, PsyD*

Department of Social and Psychological Studies, Karlstad University, Karlstad, Sweden

ARTICLE INFO

ARTICLE INFO

Article History:
Received 9 July 2021
Revised 8 December 2021
Accepted 12 December 2021

Abstract

Objective: To investigate Internet forum users’ views and experiences of melatonin treatments for troubled sleep.

Design: A thematic analysis of online disclosures about melatonin treatments was conducted.

Setting: The largest Swedish Internet forum (Flashback.org). Key search terms were melatonin and circadin/cirka.

Results: The search generated 2669 posts from 857 unique profiles in 174 different threads, posted between September 2004 and January 2021. The thematic analysis resulted in 4 themes: (1) being one’s own pharmacist, (2) wanted and unwanted effects, (3) history of unmet needs, and (4) national guidelines and clinical practice.

Conclusions: The current study suggests that experiences with melatonin treatments are diverse, and the views on exogenous melatonin polarized, albeit with a general consensus on the importance of individual factors when it comes to administration and efficacy. The study also suggests that there is an extensive off-label use of melatonin (eg, younger patients and longer treatment periods than indicated). More studies on melatonin treatments are warranted to bridge the gap between scientific knowledge and clinical practice.

© 2021 The Authors. Published by Elsevier Inc. on behalf of National Sleep Foundation. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)

Introduction

The use of exogenously administered melatonin has increased yearly in Sweden since its introduction as a drug in 2008, with a large increase since 2015.1 The increasing number of melatonin prescriptions is thought to be related to increasing numbers of individuals diagnosed with attention-deficit/hyperactivity disorder (ADHD), depression, and anxiety. Melatonin is also perceived to have fewer severe adverse effects compared to other sleeping medications.1 In 2019, melatonin was most frequently prescribed to adolescents aged 15-19, 5.8% and 4.4% of all Swedish girls and boys in this age group, respectively.1

Melatonin was approved for the treatment of insomnia in adults (55+) in the EU in 2007. In recent years, it has also been approved for children and adolescents with insomnia and either autism spectrum disorder or Smith-Magenis syndrome after sleep hygiene measures and routines have shown to be insufficient.2 In the United States, melatonin is partly a complementary and alternative medicine and partly considered an over-the-counter dietary supplement. It is therefore unregulated for the most part. It is one of the most frequently prescribed medications for children in the United States, even though it is not approved by the US Food and Drug Administration for medical use.3 The current knowledge about the efficacy, safety, and clinical relevance of exogenous melatonin shows discrepancies,4-6 which is why more and larger studies are warranted, including studies on long-term effects and studies on how people view and experience the treatments.

In Sweden, the time-release melatonin drug on the market is Circa.

Circadin was approved in the EU in 2007 for treatment of insomnia in patients aged 55 years and older,7 which is equivalent to the guideline for indicated use in Sweden.8 Additionally, a few different fast-dissolving melatonin drugs can be found on the Swedish market (eg, Melatonin AGB), which is officially prescribed for short-term treatment of jet lag in adults and for insomnia in children and adolescents ages 6-17 with ADHD.9 Melatonin AGB was subsidized for all ages and diagnoses until March 2021 but is now only covered by the Swedish out-of-pocket cost ceiling for children and adolescents with ADHD,10 as opposed to Circadin, which has never been subsidized. The out-of-pocket cost ceiling for pharmaceuticals ensures that everyone pays a maximum of 2225 SEK ($278) during a twelve-month period regardless of the number of pharmaceutical treatments one receives during this period. This is relevant because patients’ financial situation may affect which preparation the physician prescribes.

*Corresponding author: Siri Jakobsson Støre, Department of Social and Psychological Studies, Karlstad University, Karlstad SE-651 88, Sweden.
E-mail address: siri.store@kau.se

https://doi.org/10.1016/j.sleh.2021.12.005
2352-7218/© 2021 The Authors. Published by Elsevier Inc. on behalf of National Sleep Foundation. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)
Research studies have documented the effectiveness of exogenous melatonin in reducing subjective jet lag and improving sleep for travelers, reducing sleepiness and increasing total sleep time in shift workers, and decreasing sleep onset latency and increasing total sleep time in children (albeit not adults) diagnosed with delayed sleep-wake phase disorder (DSWPD). A few case reports and exploratory studies have shown positive effects from melatonin treatments in inducing and maintaining sleep in children with neuropsychiatric or neurodevelopmental disorders. Some reports have also indicated positive effects of melatonin treatments in adults with insomnia, yet those treatments are not recommended due to insufficient empirical evidence to support such treatments with this patient group. The research on melatonin treatments is dominated by quantitative studies. A few qualitative interview studies have explored views and experiences of melatonin treatments in people with schizophrenia and schiz-affective disorders, people with progressive multiple sclerosis, and parents about their children’s melatonin medications. This should be studied with other participants in other settings (eg, adolescents in child and adolescent psychiatry). Other qualitative methods of data collection should also be considered.

Internet forums are central social arenas for many young people and, therefore, can provide important research data, despite the difficulties that can be encountered in assessing the validity of the information found on them. Furthermore, researchers have highlighted the importance and advantages of employing qualitative methods to study sociocultural factors and everyday behaviors that lead to national, and possibly global, trends and patterns in drug use. Consequently, the aim of the current study was to analyze Swedish Internet forum users’ views and experiences of melatonin treatments for troubled sleep, as disclosed on the Internet forum Flashback.

Methods

The raw data for this study consisted of anonymous self-reports published on the largest Swedish Internet forum, Flashback. It is a general discussion forum covering a wide range of topics, and users are free to express however they feel, with the exceptions of hate speech, threats, and links to illegal material. Key search terms were melatonin and circadin/cirkadin. Braun and Clarke’s thematic analysis, which is a widely used method for identifying, analyzing, interpreting, and reporting recurring patterns in qualitative data, was used. The first phase of data analysis entailed getting familiar with the data by reading and re-reading the posts. In the next step, the posts were analyzed inductively for their core topics. For each new relevant topic, a code was created. The third phase involved a systematic analysis of the selected extracts to perform the current report was produced.

The anonymous self-reports analyzed in this study were publicly available online. No interaction took place with the forum users. The data collection was, therefore, considered an observation of online public behavior, which falls under the Secretary’s Advisory Committee on Human Research Protections guidelines. Pseudonyms and URLs were removed from the data set for further protection; in addition, all reported extracts were translated from Swedish to English, and hence, minor alterations were made.

Results

Using the search terms melatonin and circadin/cirkadin, the author collected a total of 2669 posts in 174 different threads, posted between September 2004 and January 2021. The posts were written by 857 unique profiles, which does not necessarily equate to 857 individuals, as the users may post through more than one profile. Gender and age of the users were not identified, but the author perceived a vast majority to be young males based on the pseudonyms used, the profile pictures, and the content of the posts. The data resulted in 39 codes, which were merged into 4 themes: (1) being one’s own pharmacist, (2) wanted and unwanted effects, (3) history of unmet needs, and (4) national guidelines and clinical practice in Sweden. The themes are presented below with illustrating quotations.

Being one’s own pharmacist

The first theme addresses the forum users’ strong interest in and knowledge about exogenous melatonin and drugs in general. The users consulted each other, gave their best advice, and discussed relatively advanced aspects of the pharmacokinetics (ie, absorption, distribution, metabolism, and excretion) of melatonin. Although many people positioned themselves as specialists, a consensus existed on the importance of individual differences regarding the administration and efficacy of exogenous melatonin.

The forum users discussed, in detail, the optimal dose, timing, and duration of the effects. For example, differences between fast-dissolve and time-release melatonin and their pros and cons were frequently debated:

No, it’s not the same thing, even though they have the same active substance. Circadin is a depot tablet [time-release], which means that it emits just a little bit of melatonin continuously for several hours, whereas 5 mg of melatonin emits all melatonin at once. (Post 1, 2013)

A few active forum users continuously advised others to lower their dosages for a better effect. Some went even further and suggested micro dosing melatonin, arguing that less is more when it comes to melatonin. A few of these posts appeared to be written by users who had a strained relationship with pharmaceuticals. Some people explicitly communicated their pharmacophobia. Of course, the complete opposite was true for other users, who conveyed liberal views on drugs and/or risk-taking behaviors, but most people fell somewhere in between these extremes. Many users, though, perceived themselves as experts in optimal administration of melatonin. This may have been without any medical training when this was not stated. Also included under this theme are accounts about specific melatonin products, whether one can develop a tolerance for melatonin in terms of needing to increase the dose over time to get the same effect, whether exogenous melatonin can affect the endogenous production, and posts about drug interaction effects and long-term use.

One thing that stood out in the material was the extensive noncompliance (ie, not taking melatonin as indicated). Not so much those that reported having overdosed (ie, taking more than what the prescription said), even though some did report taking such actions to an extreme extent. More startling was the phenomenon of tablet-splitting to alter the effect of time-release melatonin. Several people had allegedly been advised to do so by the same person who wrote the prescription:

Try to crush them. That’s what my physician told me. Then you get a fast dissolving effect instead. I got fast-dissolve melatonin after that, which goes under the out-of-pocket cost ceiling. (Post 2, 2015)

A few forum users did not want to split their tablets, as it reminded them too much of preparing to use narcotics, and they did not want to fall into old behaviors. Some users had tried to snort melatonin to get intoxicated and described the incredible pain that followed.

Wanted and unwanted effects

The second theme is about the positive and negative short- and long-term effects the forum users had experienced from exogenous
whether exogenous melatonin actually works. A few people felt that their sleep had deteriorated because of the melatonin treatment. Taken together, the forum users expressed different views on whether exogenous melatonin actually works.

Several users described an altered emotional state for the better after the initiation of exogenous melatonin. They described feelings of happiness, euphoria even, and alertness as the result of sleeping for the first time in a long time. Some of the other users, however, described mild to severe adverse effects of their melatonin treatment. For instance:

The first night on Circadin I fell asleep fast and had a restless sleep. I got feverlike sweats, and in the morning when I woke up, I puked! I thought I was sick, but I read on the package leaflet that it was a side effect... I got watery eyes and stomach pains, and it affected my short-term memory as well. Circadin helped me fall asleep, by all means, but after a week, I felt more anxious during the day, and that was the straw that broke the camel's back. (Post 3, 2012)

Adverse effects had occurred with prescribed melatonin and imported supplements alike. Many users appeared to interpret all symptoms they or others had experienced as side effects of the melatonin treatment. Occasionally, the logic of this was questioned by their peers on Flashback.

History of unmet needs

The third theme portrays the experiences the users had with exogenous melatonin in light of their psychiatric histories, absence of structure, and experiences with stress and trauma. Many people felt they had been incorrectly treated in the past, such as being diagnosed with the wrong (sleep) disorder or receiving medical treatment only for their sleep problems in the midst of trauma. Many expressed feelings about not being seen, heard, or understood by people they depended on for help when they were at their most vulnerable.

Many forum users described a long history within psychiatry, where most seemed not to have tested other treatment methods besides medication for their sleep problems. Psychologists and psychotherapies were almost totally absent from the disclosures, even when the users described concurrent anxiety, depression, and suicidal ideation. Many forum users had, on the other hand, tested a multitude of drugs. The users discussed the importance of so-called sleep hygiene to a great extent, in terms of being exposed to more daylight and less blue light from screens, reduced caffeine intake, and so on. There were users who claimed this to be enough, while others thought of melatonin treatment as the last piece of the sleep puzzle:

I consulted my physician, but he turned me down and told me to keep my room dark, don’t drink coffee, etc. (which I don’t anymore, hello decaf!), but I’m dead sure I have DSWPD (delayed sleep-wake phase disorder). I should probably take Circadin? I should probably look for another physician as well. (Post 4, 2012)

A few of the users described a strong preference for staying up and working at night, with no wish to change through medication:

I don’t understand why all physicians are so stubborn with trying to make me alter my circadian rhythm. I’ve been on sick leave for a very long time, and I’m awake at night, and this is perceived as the reason for me not getting better. I usually work night shifts, just because I’ve never been able to sleep during the night. Since I got a new job and could work during the night, I’ve felt so much better, compared with all those years I tried to adapt to daytime work. I could oversleep even when my shift started at noon. It’s when I have to adapt to the “normal” that I feel sick... I LOVE being awake at night, but apparently, that’s not ok. (Post 5, 2008)

National guidelines and clinical practice in Sweden

The last theme is about the forum users’ experiences with exogenous melatonin in view of specific guidelines and clinical practice in Sweden. It is, perhaps, really about the medicalization of sleeplessness in a Swedish context. The data suggest that there is an extensive off-label prescribing of melatonin in Sweden (eg, younger patients and longer treatment periods than indicated), inevitably affecting how the forum users perceive the guidelines and those who represent them. Many users also had experiences with illegal import of melatonin supplements.

In numerous posts, the users discussed their thoughts on melatonin being classified as a drug, as it is in Sweden, as opposed to it being considered a supplement one can buy over the counter in a pharmacy, as is the case in many other countries. A general distrust regarding physicians and other health professionals, pharmaceutical companies, and the wider society was also expressed in many posts, to the extent that a few of the users felt the need to defend physicians:

A good physician will try to prescribe fast-dissolve melatonin so that the patient doesn’t have to pay 300 kroner each month for a drug that’s not subsidized and a drug with a depot effect that’s only approved for patients older than 55. It’s not the physician’s fault; the problem is the regulations from the Swedish Medical Products Agency. (Post 6, 2015)

Many forum users had experiences using imported melatonin supplements to save money, even after melatonin was classified as a drug, which made it illegal to import melatonin. Such disclosures decreased over time in as it became easier to obtain a physician’s prescription. A couple of users experienced packages of illegal imports being taken by customs but said that it only happened about one out of ten times. None of the posts indicated any penalties for the detected packages. Some users stated that they did not know that it was illegal to import melatonin supplements, while others were very aware of it:

If the customs were to confiscate my melatonin, do I risk any penalties, or will they turn a blind eye? As a pharmacist, I can’t say that I didn’t know that it was illegal to order drug-classified substances from outside the EU. So, should I order it in my own name or in my nephew’s name? I have a couple of warnings from my employer already, so I don’t want to get caught for something as simple as this. (Post 7, 2012)

Some users had bought their melatonin when abroad or on the so-called darknet. Others argued that prescribed melatonin is of better, or at least known, quality and, therefore, is a safer option compared with imported supplements. A few confessed that they were selling their melatonin tablets to other people or giving them away to friends and relatives. A couple of users even tried to sell melatonin products through the forum, but this was frowned upon. Over time, more and more people were questioning why users still bought melatonin supplements instead of going to their physicians to get proper treatments.

The earliest posts were written before melatonin was introduced as a drug in Sweden in 2008. In posts around that time, users asked for advice regarding what to say to their physician to get a
prescription for melatonin, while many had been dismissed by their physicians when they had mentioned the subject. In later posts, several forum users described getting melatonin “thrown at them,” as it had come to be perceived as the safest option. The forum users deliberated on the role large pharmaceutical manufacturers play regarding what is being researched versus what is not being researched and why. The users also thought it was problematic when physicians rely more on their clinical experience than on the empirical evidence. Many of the forum users linked to scientific studies to back up their arguments and did not accept anything less from their physicians:

“It’s interesting how uncritical the view on melatonin is in Swedish psychiatry today. I read somewhere that the prescriptions have exploded in just a short time, and I have, just this year, met several chief physicians who—without being able to really explain why—praise melatonin as the best sleep medicine ever, even though many patients, myself included, have tested it several times in different doses without any effects…. I’m not saying that melatonin doesn’t work for anyone, but to say that it works for almost everyone, and if it doesn’t work, explain it away with quasi-arguments, like “you need to increase/lower your dose” or “you need to test another preparation,” just shows how ridiculously uncritical the attitude toward this drug has become. (Post 8, 2018)

Many users described feelings of being like lab rats, as they pointed to the gaps in the research, demanding that more research be done.

Discussion

The current study aimed to explore Internet forum users’ views and experiences of melatonin treatments for sleep problems. Melatonin was described as everything from a magic cure to a “sugar pill” with no effect. A few of the forum users kept advising others to lower their doses of melatonin to get more positive effects. Some of the users were also splitting their tablets, either to obtain a smaller dose (fast-dissolving melatonin) or to alter the effect (time-release melatonin). This goes against the guideline for indicated use of Circadin, which explicitly states that one “may not crush or split Circadin tablets.” Interestingly, some of the users wrote that they had been advised to do so by their own physicians. That so many forum users reported experiencing adverse effects was another interesting finding, as most scientific studies on melatonin treatments report very few side effects. This is, however, in line with Khan et al. (2018), where one out of 5 themes in their thematic analysis covered experiences of “negative effects,” with a subtheme dedicated to “unusual side effects.” The reported adverse effects in the current study may have been affected by factors such as the forum users’ expectations, reckless over- and misuse, and drug interaction effects.

Some people had experienced effects of the melatonin treatments for symptoms of anxiety and depression, in line with what we know about the bidirectional relationships between these conditions. The very few disclosures about nonpharmaceutical treatments in the data, even when comorbid anxiety, depression, and suicidal ideation were discussed, suggest a medicalized psychiatry and, more specifically, a medicalization of sleeplessness, in line with Moloney et al. even though drug therapies are the natural focus in threads about melatonin treatments. National and international guidelines for sleep treatments recommend nonpharmaceutical interventions first, and that pharmaceutical treatments should only be given after careful consideration and for a short period of time. The current study suggests that such guidelines are not always followed. Most sleep medications have only been studied with adult patients and are, therefore, only approved for adults. Thus, more rigorous, large-scale clinical trials on melatonin treatments are needed to ensure the long-term safety, efficacy, and clinical relevance of exogenous melatonin for all age groups.

Many forum users had experiences with illegal import of melatonin supplements to save money due to certain melatonin drugs not being covered by the Swedish out-of-pocket cost ceiling for pharmaceuticals. This undoubtedly affects which drug physicians prescribe, based on factors such as the financial situation of the patient, and further, raises questions of untailed treatments and of health equity. It can potentially lead to the overdiagnosis of ADHD. Insomnia is a frequent side effect of stimulant medications. Prescribing an additional drug is possibly regarded as the easiest and quickest solution to solve this problem.

A qualitative study is a good option when the current knowledge shows discrepancies or contradictory results, as is the case here. A qualitative study can also focus on other study objectives, such as peoples’ views and experiences, and help answer research questions that a quantitative study often cannot answer in depth. The current study adds to the limited qualitative empirical evidence on melatonin treatments that exists, with another group in focus, and with a novel method of data collection (ie, Internet forum users’ online disclosures). Internet-based data can be argued to have high ecological validity (ie, generalizability to real life settings), because the data have been produced in an environment with a means of communication with which the users are familiar. The forum appeared to be a safe space for many people, at least in the threads concerning melatonin treatments. The users asked for tips and support and gave each other their best advice. Many posts were long, diary-like, and full of pain and despair, but also reflected humor and hope. Another advantage with the current study is that it was not limited to socially acceptable and curated answers, as social desirability bias—giving socially desirable responses instead of true answers—has been found to be a major issue in studies on sensitive topics, drug use included.

Many forum users described feelings of social marginalization. Many felt neglected by both healthcare personnel and the research community. Some users explicitly requested that more research be done on melatonin treatments but would perhaps not participate in conventional studies themselves.

One disadvantage with collecting data through the Internet is that it is impossible to establish the identity of the subjects, although this is part of the strengths mentioned above. This is especially true in a study like the current one, where the data consist of written comments, and it is impossible to ask any follow-up questions. One cannot be sure that what the users disclosed was true in an objective way, so to speak, but this is also true for conventional qualitative data (eg, interviews) and even several types of quantitative data (eg, survey data). The language and content of the posts were deemed authentic by the author. Furthermore, the focus of the study was on the patterns of views and experiences more than on individual accounts. Another limitation is whether the results of the current study are generalizable to nonforum users’ experiences with melatonin treatments. Therefore, further studies in other settings and with both adult and adolescent participants (as 15–19 is the age group of which melatonin is most frequently prescribed, at least in Sweden) should be conducted. Until we have a fair degree of empirical certainty about the efficacy, safety, and clinical relevance of melatonin treatments for all age groups, physicians are encouraged to contemplate whether all their patients with melatonin prescriptions really have a melatonin deficiency that needs to be medicated, for how long, and whether less actually could be more.

Conclusions

The aim of the current study was to analyze Swedish Internet forum users’ disclosures of their views and experiences of melatonin
treatments for troubled sleep. The analysis resulted in 4 themes: (1) being one’s own pharmacist, (2) wanted and unwanted effects, (3) history of unmet needs, and (4) national guidelines and clinical practice in Sweden. This paper suggests that the forum users’ experiences with exogenous melatonin were very diverse, and their views were polarized, albeit with a consensus about the role of individual differences regarding the administration and efficacy of melatonin treatments. In the larger picture, the study suggests that the guidelines regarding indicated use of melatonin products may be systematically overlooked, warranting more studies to bridge the gap between scientific knowledge and clinical practice.

Declaration of conflict of interest

The author has no conflicts of interest to declare.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Acknowledgments

The author would like to thank Jennifer Strand, Johan Green, Annika Norell-Clarke, and Maria Tillfors for valuable comments on the manuscript.

References