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Narcolepsy: Awakening to a New Day in Its Management

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Julie Flygare:
I feel like my life is just really spiraling out of control recently. Law school feels super important to me, but somehow the connections just aren’t really working. I’m reading my textbook material, but I can’t seem to remember, even if I’ve read the same case 3 or 4 times. And recently, I’m even having trouble driving even 15 minutes to school in the morning, after getting a full, 8-10 hours of sleep. I drove to school recently 15 minutes, and I couldn’t remember pulling into school or choosing a parking spot. I was okay, but that really, really, really scared me, and I thought for the first time, like, maybe I have a sleep problem. There are also times when I’m laughing at jokes, and my knees are slightly buckling or slightly melting under me. I’ve asked multiple doctors about this, and no one really seemed to know what that is. And to me, I feel like that’s a completely separate issue that I have to address right now. I’ve also had times when I think a burglar is breaking into my apartment, and I’m really terrified, but I can’t seem to move and respond and run away. And then I’ll look around again, and there’s no burglar and there’s no sign of any break-in. So I’m really hoping that goes away soon, and it’s not really something I want to bring up to a doctor. Sounds pretty weird, and I’m just really wondering why all of these things are going wrong all at once.

Dr. Kuritzky:
Julie, thank you for sharing your story. This is CME on ReachMD. My name is Louis Kuritzky. I’m a family medicine physician, and I’m certified as a specialist in hypertension. The story we’ve just heard is a story that many primary care clinicians might not necessarily piece together as well as Julie has for us. We need to learn a lot more, and we’ll be sharing the opinions of two sleep experts, Drs. Zee and Doghramji.

Dr. Zee:
Thank you. I am Phyllis Zee. I’m a neurologist at Northwestern University. I also direct the Sleep Disorder Center.

Dr. Doghramji:
Hello. I’m Karl Doghramji. I am a sleep specialist and a psychiatrist, and I direct the Sleep Disorder Center at Thomas Jefferson University in Philadelphia.

Dr. Kuritzky:
We’re going to dive right in, and we know that the door through which patients with sleep disorders enter can be quite diverse, ranging from primary care through neurology, pulmonology, psychiatry, ENT, and other specialties. So these things can sometimes accelerate the process of diagnosis, and sometimes delay. We need to all find better ways to identify the patients who have sleep disorders, optimize their diagnosis and treatment, and minimize delays. After you’ve heard our patient discuss the dilemma that she was presented

with because of her narcolepsy, what comes to mind?

Dr. Zee:
Julie's experience really resonates very well with many of my patients. I think a lot of patients just don't recognize that their tiredness, that their mental fogginess is really, perhaps, excessive daytime sleepiness. It's the little symptoms that are really chronic. Patients also don't appreciate how bad it is because they've been living with it all their lives, and I think some of my patients say, "Well, people may think I'm lazy." Or they're describing things like, you know, these weird, vivid dreams and experiences. They may even think that they're a little bit goofy. So they're hesitant to talk to their doctors about that. So I think it's really important for us to be really proactive. I ask all my patients are they sleeping well? Are you too tired during the day, so that you can't do the things that you need to do? Are you sleepy during the day, and is that affecting the quality of your life? And if the answer is yes, then I proceed, you know, to dive a little bit deeper into trying to understand what may be causing this excessive daytime sleepiness.

Dr. Doghramji:
Julie's case really points out some of the impairments that narcolepsy can cause – impairments in everyday functioning, such as focus concentration, memory, and even mood. You know, in many cases, these types of impairments lead to real problems, such as accidents lower performance in school on the job, breaches in relationships and so on, so narcolepsy's truly an impactful condition.

You know, and in addition to narcoleptics themselves not recognizing some of these symptoms as being problematic, medical professionals, as well, sometimes do not. Studies indicate that physicians in general are not that great at identifying daytime sleepiness, even though they exist in so many of our patients. As a psychiatrist, I know that excessive sleepiness exists in many depressives, bipolars, seasonal depressives, but often we don't identify those as such, and/or treat them. In addition, with narcoleptics especially, there's a great deal of misdiagnosis. You know, Julie describes this sensation of her legs buckling and her misperceiving something, misperceiving this burglar. These are symptoms which could easily be misdiagnosed as primary psychiatric disorders or neurologic conditions. And for all of these reasons, tragically, many narcoleptics are not identified readily and go on for years and years – a mean of 10 years before properly being diagnosed, during which time they're impaired. So I think this case is really a great one because it really shows us some of these problems with improper diagnosis, misdiagnosis of narcoleptics on a medical/professional front.

Dr. Kuritzky:
I think Julie's description of her life spiraling and coming apart should ring the bell to primary care clinicians that this is not a minor league disorder. When a patient like Julie comes in and she's telling us that she's tired, don't we need to look for red flags like cataplexy or persons who are having unusual dreams or sleep paralysis?

Dr. Doghramji:
I just want to just backtrack and mention that narcolepsy itself has a host of specific symptoms, which we might want to review. First of all, the cardinal symptom of narcolepsy is, of course, daytime sleepiness. And daytime sleepiness can have many manifestations. It can exist as a sort of a chronic level of sleepiness, fatigue, mental slowing. But on top of that, many narcoleptics have this need to have voluntary sleep episodes, or naps. They nap to mitigate or diminish the degree of their sleepiness, and some have involuntary naps. That is, they fall asleep, have these sleep attacks. Narcoleptics also have what we call "REM-related" symptoms, or symptoms of abnormal REM sleep. REM occurring at a time when it should not occur. The cardinal, most important of which, is cataplexy. Cataplexy is a brief, sudden loss of muscle ability or control. Usually, it's precipitated by a strong emotion, like laughter, surprise, or anger. Another symptom of disrupted REM sleep in narcoleptics is something called hypnagogic hallucinations. These are vivid, dreamlike experiences, which occur during the transition from wake to sleep. Some experience it in the form of a hallucination. As you can also imagine, this can be easily mistaken for a primary psychiatric disorder. And finally, something called sleep paralysis where, as they're lying in bed, they experience an inability to move. It's a temporary inability to move their muscles. Many narcoleptics also have very disturbed nocturnal sleep. So this is the constellation of narcolepsy. So when we see somebody with sleepiness, I think it's important to ask about these symptoms, to see does the patient have narcolepsy.

I think there are many ways to diagnose the condition in a definitive fashion. I'll just mention that there are two general diagnostic nosologies. One is the International Classification of Sleep Disorders, and the other is the DSM. Just quickly, in the ICSD, or the International Classification of Sleep Disorders, there are two types of narcolepsy. Narcolepsy type 1, which is also called narcolepsy with cataplexy, and narcolepsy type 2, which is also called narcolepsy without cataplexy. The DSM-5, or the Diagnostic Statistical Manual in psychiatry, is a bit different than the ICSD. In addition to sleepiness, it also specifies that patients should have cataplexy, but it doesn't necessarily mandate the testing with MSLT [multiple sleep latency test] or sleep study to diagnose narcolepsy. So unlike the sleep nosology, the psychiatric nosology does not mandate a sleep study for diagnosis. Now this is a controversial area, but some of us believe that this may be useful for some narcoleptics. In special circumstances, for example in some cases a sleep study may not be available, so the DSM diagnostic nosology may be more useful. Also in some cases, these sleep studies themselves, the MSLT studies, may also be falsely negative.

Dr. Kuritzky:
How do you think we should be inquiring about the concept of cataplexy, since that's probably going to be the most common patient scenario we might see? Could you help us with that?

Dr. Zee:
I think cataplexy is definitely the most important thing to try to elicit because, like Karl said, you can diagnose narcolepsy with that. It can be quite subtle. It's not like just people dropping and falling. It could be just a little weakness, like Julie said, in her knees. It could be sagging of the jaw. Somebody's eating, they may not be able to close their jaw.

The other thing that's very interesting about patients with narcolepsy, is that when they take naps, very short naps, 10-, 15-, 20-minute naps are refreshing. It's a little pearl there. Ask the patient who says, "I'm so sleepy all day long," ask them, "Do you take naps?" "Well, I don't try to." "But are your naps refreshing?" That really is a distinguishing factor.

Julie Flygare:
The first time I saw the word narcolepsy, I thought, "I don't have that. That's a joke about someone falling asleep while they're standing or in the middle of a sentence. That's not what's happening to me."

Dr. Kuritzky:
For those of you who are just tuning in, my name is Louis Kuritzky. I'm a family medicine physician, and you're listening to CME on ReachMD. With me today are two experts in the field of sleep medicine.

I just listened, for instance, to a podcast that talked about evolving research, with newly available therapies and some on the horizon to help people who have narcolepsy and present with, especially, cataplexy and excessive daytime sleepiness. Dr. Zee, could you give us the bird's-eye view of what's been happening in the most recent evolution in knowledge about therapies for narcolepsy?

Dr. Zee:
Before we talk about pharmacological therapy, I really want to stress that behavioral therapy, and really look at the social constructs of the patient, the family – all of that's really important. Scheduling naps can be quite effective, if you're able, for example, to do that. And talking about new things under the horizon, there's CBT for narcolepsy under development, so this is cognitive behavior therapy for narcolepsy.

But it's really been a very exciting, I think few years recently, from the narcolepsy standpoint, because there's, one, new mechanism of action that's been approved by the FDA which is pitolisant, which is a histamine receptor, works on the histamine receptor. There has also been solriamfetol, which treats the daytime sleepiness in patients with narcolepsy, as well as in sleep apnea. And I think, also, sodium oxybate is a classical medication for the treatment of narcolepsy, with sleepiness and cataplexy. But what's new is that there is a low-sodium version of sodium oxybate, and this is especially important for those individuals who are at risk for cardiovascular disease.

What's really exciting, I think, is that there are new medications on the horizon that are under development that can either further increase our ability to tailor and personalize treatment. So for example, there are the orexin receptor agonists. That's actually really getting right at the mechanism of narcolepsy. There's also the once-nightly dose of sodium oxybate, which really could benefit some patients who have difficulty waking up in the middle of the night and therefore may potentially also improve adherence.

Dr. Doghramji:
It's very much of an exciting time for us in the treatment of narcolepsy because there are so many medications, and they do offer us multiple choices. We can now tailor the medication to some of the specific clinical characteristics of the patient.

Dr. Kuritzky:
So, Julie, you may not be a health professional who reads the evolving literature on medicine, but the information that Dr. Zee has just shared, how does that help you to make your decision? Because we want this to be a shared thing. We're not saying your doctor says you have to take this. How does that information you've just heard about drugs that are on the horizon affect your thoughts and what you would like for your healthcare of this disorder?

Julie Flygare:
Well, it really makes me very excited for the future. Of course, I'm a creature of habit, so I'm used to what I'm used to, but I think, you know, the idea of having a once-nightly version of sodium oxybate sounds really exciting. There are a lot of challenges. It's not so easy as just wanting to wake up in the middle of the night or not wanting to. Waking up in the middle of the night is a challenge for me almost every night. So I really do look forward to that development, along with the orexin agonists, to me, are just really exciting for the future, to see what could potentially be to improve my daily life and the lives of many other people around the world.

Dr. Doghramji:
What would you suggest would be a good approach to our colleagues in primary care, to be able to have them properly identify these areas and to treat them?

Dr. Kuritzky:
So what I hope my colleagues will take away from hearing the insights you two have provided is, it's worth developing at least a two-step process. Be wise enough to inquire into excessive daytime sleepiness. And then, once you do, be additionally vigilant enough to know the key questions, those red-flag markers that could tune you in to this very consequential disorder, especially with something like cataplexy, and be willing to refer early.

Dr. Zee:
I think sleep should be a vital sign, and sleepiness – it's a vital sign. It means something is wrong. There's an underlying problem. It could be narcolepsy; it could be something else – any other cormorbid medical, psychiatric, and/or sleep disorder, so I think it's really important to ask. The other thing I just want to bring up is that let's not forget the need for social support for these patients with narcolepsy in the way we're treated. It's really multimodal and does take a village, like we were mentioning earlier, and social support. Project Sleep that Julie represents, it's a great place to go for the social support, but also just be able to talk to others.

Dr. Kuritzky:
So let's just take a few seconds and give our final takeaways.

Dr. Doghramji:
Number one, excessive sleepiness is a common, highly impactful problem not commonly reported and frequently missed by physicians. So look for symptoms of daytime sleepiness. Screen for sleepiness. Use the Epworth Sleepiness Scale if you can. Number two, if you identify daytime sleepiness, do a systematic evaluation, just like you would for fever, abdominal pain. Do a systematic evaluation. Look for the underlying causes – narcolepsy, sleep apnea, sleep deprivation, medication, so on and so forth. Number three, if you suspect narcolepsy, refer for diagnostic testing whenever possible and start treatment quickly. Remember we said that narcoleptics live for 10 to 15 years before becoming diagnosed, during which time they're impaired. If you suspect, refer for diagnosis, treat early.

Dr. Kuritzky:
So we're out of time, unfortunately. I've really enjoyed our colleagues' comments. I want to thank Drs. Doghramji and Zee for including my primary care colleagues in the conversation and giving us the insights that we can gain from the generosity of Julie sharing her story with us. And so it was great speaking with you today, and I hope our colleagues have gained new knowledge and enthusiasm and rationale for why it's worth looking at a disease that is not a unicorn – narcolepsy. Thank you and good night.

Dr. Zee:
Thank you.

Dr. Doghramji:
Thanks.

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