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Lessons Learned from a Narcolepsy Support Group

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Abstract

As a sleep physician for a military treatment facility our patient population consists of roughly forty thousand soldiers and beneficiaries. Of which we primarily care for an adult population. Part of my experience as a sleep physician has involved the use of group classes and support group sessions for obstructive sleep apnea, insomnia, oral appliance therapy and nightmare therapy groups. I wanted to establish a support group within our clinic for patients with narcolepsy.

Keywords: Narcolepsy; Modafinil; Xyrem; Support; Epworth sleepiness scale

Introduction

Narcolepsy is a relatively uncommon diagnosis in a primary care setting, occurring in one 0.02-0.05% of the population within the US and Europe [1]. However, in a sleep clinic due to referral bias concentrating cases from a larger area, any sleep clinic may have anywhere from a handful of patients with narcolepsy to several hundred at large sleep centers. One common theme I have found amongst narcolepsy patients is a profound sense that they are alone or unique in their symptomatology. They have never met anyone else quite like them. They had met people who were tired, as they had known what it was like to be tired before having narcolepsy. But they have never met anyone else who needed sleep the way they did, anyone else who would schedule their lives so meticulously around nap opportunities. Because I have seen so many patients with such similar stories I decided to hold a support group for narcolepsy patients and these are some of the lessons I learned from leading the group.

Keep the sessions informal: Start each session with brief introductions and ground rules for the discussion. I asked that no single person talked for more than a few minutes without letting others contribute. It was a meeting for everyone not any one person to talk. I wanted to be sure that stronger personalities didn't overpower the conversation, leading to introverted ones being left out. However this never materialized as a significant problem. Have sessions infrequently. We chose to have sessions every 2-3 months so it keeps its novelty but does not feel like a chore. The participants look forward to seeing the other patients and after every session ends they continue to converse outside the clinic even after the hour to an hour and fifteen minute session ends.

Have one sleep staff serve as the moderator to prompt conversation, questions and steer conversations in productive directions. While different staff attended each meeting, one of the sleep physicians was in charge to lead the session. Most of the talking came from the patients. I had hoped over time that staff would not be necessary to lead the sessions, but in the small groups we held, leaders did not emerge to take charge of the sessions. Possibly because one of our staff was already filling the moderator role or possibly because our clinic is on a military base and in a military culture rank usually takes charge. But in a room of strangers, most of them wearing civilian clothes, not uniforms, it is hard to figure out who would be the one in charge. So staff served as moderator and discussion leader.

Prompt the group with simple, common questions, or symptoms and watch them get excited talking about them. For example, “what do your partners or coworkers think about your diagnosis?” “When is the toughest time of the day for you to stay awake?” “Describe what cataplexy is for you?”

If you ever get stuck or the conversation drags down simply ask about medications. “So and so is new to the group and isn't aware of all of the medications. Can you guys talk about your experiences with medications?” Sit back and watch them go and they'll ask the questions for you. On occasions I chime in and ask things like; “what do you think about your medications?” “Which medications are you taking or which medicines have you taken?” “What side effects have you noticed?” This type of questioning alone can last the full hour.

The medication questions bring out some of the most insightful and surprising answers for me as a provider. The individual response to medications is varied. Even in patients who appear to be having a good response and are reporting improved daily functioning and Epworth sleepiness scale scores they still have frequent sleep attacks, micro sleeps, and much more frequent naps than they report in clinic. One patient who told me her mood was better and her cataplexy was hardly even noticeable anymore since starting on an antidepressant. In the group session she admitted to still having 25 cataplexy episodes per month, and that while her mood was overall better she had just had an emergency room visit due to a major depressive episode. This taught me to not listen in clinic for what I want to hear as a provider, which is that the patient is doing better, but rather specifically how much better are you doing? You say your cataplexy is rare, can you define rare? Does that mean once a day or once a week? Hearing that a patient's mood has improved is helpful, but getting some objective measure of mood symptoms such as a Patient Health Questionnaire (PHQ) or PTSD Checklist (PCL) may be more clinically valuable. We use Epworth Sleepiness Scale (ESS) scores and Insomnia Severity Index (ISI) scores frequently but in this population which has a lot of

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coexisting anxiety and depression, maybe we should do a better job of screening for and facilitating behavioral health treatment.

Often times the narcolepsy patient referrals come from behavioral health professionals. The consults say they have a depressed patient that seems to be sleeping an abnormal amount of time. Ensuring that the patients continue to receive the behavioral health support they need is paramount for their treatment success. Most narcolepsy patients have their sleepiness and energy respond well to stimulant medications, wake promoting medications, and sodium oxybate treatments but I have found both in clinic and in support group that the behavioral health burden does not improve as quickly as the excessive daytime sleepiness does.

One of the most heartbreaking things was hearing about the delay from time of symptoms until the time of diagnosis and treatment. Patients routinely describe frustration, shame and embarrassment as they tell their loved ones, primary care providers and behavioral health providers that they are tired. They are met with resistance and the impression that this is all in their heads. They are told they are depressed or just lazy. As one patient put it, “I’m not depressed and lazy, I’m sleepy and nothing I’ve tried makes it any better.” It has been reported that the average delay from time of first symptoms for narcolepsy until diagnosis for adults is eight to sixteen years [2]. In our group it tends to be shorter but still on average 1-3 years. In the military culture it is not abnormal to be sleepy. It is a macho culture of young night owls forced into early morning physical training sessions and shift work along with high operation tempo. Sleepy and Soldier go together. However the sleepiness of narcolepsy is on another level. I describe it this way: think about how you feel after working a 24 hour shift. Now imagine feeling that way every day of your life because that is what the sleepiness of narcolepsy feels like.

Maybe just as bad as the impression that the disorder is a behavioral health or motivation problem is the stigma the stimulant medications hold. Many patients describe the reaction of asking a primary care provider to refill their stimulant medications. They are received like drug seekers who must be using the medications to get high. In my professional experience I have not seen evidence of drug seeking behaviors from any narcoleptic patient. They do not push for escalating doses, nor request early refills of medications, or lose their medications. They know the medications are life changing and they need them to function, and I have not seen evidence for abuse.

I usually judge medication response off of the patients Epworth Sleepiness Scale score and adjust medications accordingly to that score. I thought this was appropriate but have had numbers that did not match up to symptomatology. For example a patient who regularly reported Epworth scores in the normal range on medications informed us in support group that he was regularly late to work due to profound sleep inertia. The Epworth is a tool but can be under or over reported.

There are three primary medication types used for treating narcolepsy; stimulant medications, wake promoting agents, and sodium oxybate [3]. Patients have varied responses to each medication and some prefer one medication to another. Of the three medication types, Xyrem (sodium oxybate) appears to me to be the most effective, particularly for cataplexy. Antidepressants can also be used but do not appear to be as effective for cataplexy as Xyrem does. For the treatment of excessive daytime sleepiness Xyrem also appears to have the strongest response. Stimulant medications seem to be the next most effective, although they do not last nearly as long as they seem to for patients with ADHD for example. Most often I find that extended release tablets are needed twice per day. The after lunch time period seems to be especially challenging, and strategic napping is a very effective tool to help with midday sleepiness. Wake promoting agents such as modafinil have the most varied efficacy. Some patients find it to be highly helpful, while others compare it to placebo. They take it but do not notice the efficacy as much as they notice it with the other two classes of medications.

In summary our experience with holding a narcolepsy support group was valuable both to patients and providers. It helped address some of the social and interpersonal aspects of the disease while helping patients feel less isolated. The time commitment was reasonable as it only took four to five hours per year and helped foster both improved communication and understanding for all involved. In comparing the narcolepsy support group to other groups we have held, the narcolepsy group was the easiest and most emotionally satisfying group. Patients are happy to attend and regularly ask when the next session will be. Providers felt better able to treat patients because they understood the effects of their treatments and patients were more aware of the treatment options available to them.

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