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Psychosocial Impacts- Impact on Employment and Healthcare Costs

Announcer:

Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

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Dr. Kushida:

This is CME on ReachMD, and I'm Dr. Clete Kushida. Here with me today is Dr. Michael Thorpy. We are looking at psychosocial impacts of the narcolepsy stigma.

So first of all, Michael, can you go into a little bit of the individual and socioeconomic burden of this topic of the psychosocial aspects of narcolepsy?

Dr. Thorpy:

Yes, Clete, so patients have really profound impact on their daily lives, and this affects them and their interactions with their family, with their friends; all their social activities are affected. But in terms of the psychosocial aspects for these patients, they really have a lot of problems.

And those that have cataplexy too, that makes it more difficult for them. They just can't live a normal life, and that if they have children, for example, it may be very difficult for them to look after those children in an effective way because they're so tired and sleepy and may fall asleep intermittently, of course. So it affects their relationships, it affects their marriage, and it affects their relationships with their family members as well.

Dr. Kushida:

Yes. And, you know, I always think of them as sort of living on a double-edged sword, because if they're in activities that are somewhat boring, then they'll start having the sleepiness or sleep attacks. But then if they get in activities that are maybe too stimulating, then there is a chance that they might get into cataplexy. So it's really almost a daily challenge to sort of balance those.

So, you know, Michael, I know you've done some work specifically in this area. So could you talk a little bit about the challenges associated with narcolepsy, both for the patients and the physicians, their providers, in this context?

Dr. Thorpy:

Well, that's right. We did a study, it was a survey, a Know Narcolepsy survey, and they showed that 74% of patients with narcolepsy missed everyday social events and activities because of the narcolepsy. 76% found that narcolepsy was negatively affecting important life moments. So whether it's marriage or going for a job interview, meeting someone for the first time, narcolepsy interferes in those activities. They also often miss important events because they may be too tired or too sleepy to be able to get to them, or it may be just too difficult because of their cataplexy. And it affects their education as well. 37% in the survey said that they had failed a class at school or withdrew because of problems related to narcolepsy.

And many patients have been fired from a job because of the narcolepsy symptoms. They often have to ask for special accommodations

at work because of their sleepiness. Many times they need to go and have a nap room where they can go and lie down and sleep. And of course, this can interfere with their work and make them more liable not to be able to keep their job because they may not be able to do that job really effectively. 60% of these subjects are worried about losing their job because of their narcolepsy.

Dr. Kushida:

Absolutely. And, you know, in that same study you also looked at patients and physicians or providers, your perceptions in respect to the challenges associated with narcolepsy. Could you also talk a little bit about that in terms of the data that was found during that study?

Dr. Thorpy:

Well, that's right. In this study they actually had physicians rate some of these quality of life issues as well as the patient. For some things, there were differences. In many cases, actually, physicians felt that the patients were worse off than the patients actually said and even overestimated the difficulty that patients were having.

But there was a common sense between both the physicians and the patients that they were severely affected in their everyday life. So it is a major concern for these patients with narcolepsy.

Dr. Kushida:

Thank you, Michael. And thank you for listening. I hope this discussion will be helpful in your clinical practice.

Announcer:

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