

## Self-Management Techniques for Excessive Daytime Sleepiness Used by Participants in a Narcolepsy Advocacy Group

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Received date: Jul 31, 2015, Accepted date: Sep 02, 2015, Published date: Sep 24, 2014

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### Abstract

**Study objectives:** Excessive daytime sleepiness (EDS) interferes with functioning and causes distress for narcoleptic patients. Self-management techniques are believed to be an important part of a comprehensive treatment plan for patients with narcolepsy. Relatively little is known about how behavioral tactics are perceived and which techniques are used more often. This study examined behavioral techniques used for EDS in a non-clinical sample.

**Methods:** A survey developed by the authors listing 16 different possible behavioral tactics plus write in options was distributed at a national Narcolepsy Network conference.

**Results:** Data were analyzed for 44 respondents who self-identified as having narcolepsy. Walking around a room was the most commonly used tactic identified by 73% of respondents. Napping ranked second, with scheduled and unplanned naps endorsed to the same degree. Talking, fidgeting and eating tied for third most cited. On a visual analog scale 0-10 with 10 high, the absolute effectiveness of behavioral techniques were rated as 7.2 and effectiveness relative to optimized prescription medication was lower at 5.3. Only 66% of respondents recalled ever having been counseled by a health care provider to try self-management techniques.

**Conclusions:** Walking around and naps were identified as the most used self-management options. Respondents viewed behavioral techniques to have moderate value. Relatively few participants recalled being encouraged by health care providers to supplement prescription approaches with self-management strategies. Healthcare providers need more familiarity with behavioral techniques for managing excessive daytime sleepiness so they can counsel patients to explore these interventions.

**Keywords:** Narcolepsy; Sleepiness; Hypersomnolence; Behavioral techniques

### Introduction

Self-management techniques, increasingly an area of focus within health care, have not been examined closely for patients with excessive daytime sleepiness (EDS). EDS is an omnipresent symptom of narcolepsy that can limit functioning and cause distress. Especially prior to the diagnosis of a specific sleep disorder, sleepy persons experiment with behavioral tactics to cope symptoms. After diagnosis many persons employ self-management techniques to augment other therapies in the context of a multimodal treatment plan.

Relatively little information is available regarding how patients view self-management techniques for managing excessive daytime sleepiness. After interviewing 20 patients Rogers listed behavioral approaches that patients utilized to cope with EDS and cataplexy [1]. Her 1984 paper does not report which tactics are more commonly utilized. Garma and Marchand in 1994 studied patients with narcolepsy who returned for follow-up after deciding to discontinue stimulant medications. This study found that, because they preferred to rely on napping, 6 of these 13 patients stopped medications [2]. In their 2007 review of behavioral techniques of narcolepsy Broughton and Murray commented that patients sought to avoid hypnogenic

situations, specifically sedentary behaviors, boredom, overly warm situations and slow rhythmic stimulation. Consciously increasing stimulation was described as “very effective” with examples of patients preferring to stand rather than sit, move about as much as possible, increase background noise, seek a cooler environment, and go outside to a more stimulating environment [3]. Several trials have produced data that scheduled naps are efficacious in reducing EDS [4,5]. Little is known about how persons with EDS attributed to narcolepsy rank specific tactics relative to one another or compared with medications.

This study was designed to solicit data regarding the participants’ perception of behavioral techniques. A non-clinical population was targeted to reach people who use self-management techniques in addition to or potentially in place of medical interventions. Questions were designed to investigate the frequency that an individual used various techniques and a global assessment of the usefulness of behavioral interventions in the management of EDS associated with narcolepsy.

### Methods

This study was approved by the Institutional Review Board of the Mayo Clinic. The authors developed a survey titled “The effectiveness of self-management strategies used to manage excessive daytime sleepiness associated with narcolepsy”. Respondents were presented

with a list of 16 self-management techniques used for EDS. The 16 tactics were selected based on information gathered from patients with narcolepsy in the course of clinical practice as well as the published reports by Rogers, Garam and Broughton [1-3]. In addition the survey included multiple spaces for the respondents to write in additional behavioral tools and comments. Three additional questions utilizing a visual analogue scale (VAS) addressed the global value of behavioral techniques and whether health providers had discussed the potential role of non-pharmacologic tactics. The survey was distributed in a hard copy format at the annual meeting of the Narcolepsy Network, a national patient advocacy organization formed in 1984. Self-reported demographic and clinical data included demographics and basic disease characteristics. Participants who self-identified as having narcolepsy were asked to provide their age at the onset of symptoms, age of diagnosis and whether they had cataplexy. Respondents indicated their implied consent to participate by returning a completed form. Data was analyzed looking at the frequency each tactic was endorsed for self-management of EDS.

## Results

The study group consisted of 44 respondents who self-identified as having narcolepsy. The respondents were 66% female, with an average age of 45 (range 19-89). The mean age of onset of narcoleptic symptoms was 17 years (range 7-60) and mean age of diagnosis age 32 years (range 17-65). Twenty-nine (66%) participants had narcolepsy associated with cataplexy. There was no statistically significant difference between respondents with and without cataplexy in the survey results. A response rate to the survey cannot be calculated since the number of attendees diagnosed with narcolepsy is not tracked. Narcolepsy Network conferences draw persons with narcolepsy as well as family members, friends and healthcare professionals.

	Rank Order	Frequency	Percentage Endorsed (%)
Walking around	1	33	75
Naps, scheduled	2	31	70
Naps, unscheduled	2	31	70
Talking to Someone	3	28	64
Fidgeting	3	28	64
Eating	3	28	64
Exercise (working out)	4	27	61
Listening to upbeat music	4	25	57
Drinking a cold beverage (not caffeine or alcohol)	5	23	52
Caffeinated beverage	6	20	46
Blast of cold air	7	18	41
Hot bath/shower	8	16	36
Smoking tobacco	8	5	11
Caffeine pills	9	3	7

**Table 1:** Behavioral techniques most often used for ED.

All respondents identified multiple techniques with a mean of 7 different tactics per respondent (range 3-13). Table 1 displays the survey data concerning preferred behavioral techniques.

The most highly endorsed tactic was physical exertion in the form of simply walking around. The second most frequently noted was napping. Respondents endorsed relying on planned naps as often as unscheduled naps. Several respondents wrote in comments that their work or school schedule prevented them from napping as much as they would like.

Working out and listening to upbeat music, tactics that represent increased stimulation, all fell in the mid-range. Caffeinated beverages were ranked considerably higher than caffeine in a pill or other formulation. No respondent endorsed nicotine in either a smokeless or other formulation i.e. transdermal nicotine. Using stimulating substances like tobacco and caffeine pills were least used of inventory of tactics. Several respondents commented that the resulting heightened alertness was too transient to be of benefit.

Overall no differences were observed based on age or gender, although there was a trend that younger patients utilized music (possibly with a convenient device like a MP3 player) more than older ones. No respondent identified simply a single technique; all endorsed a variety of tactics. Respondents wrote in a variety of additional techniques as listed in Table 2.

Keeping a regular sleep schedule
Pinching
Utilizing self-hypnosis
Massaging
Tickling
Utilizing biofeedback
Avoiding anti-inflammatory foods
Knitting
Listening to books on tape while driving
Yelling at self
Splashing water on face

**Table 2:** Other tactics written in by respondents.

Only 29 (66%) respondents could recall ever discussing behavioral techniques with a health provider. The VAS (0 never, 10 frequently) measuring how often health care providers had encouraged use of self-management techniques generated a mean of 3.8. Participants also provided a global impression of the effectiveness of behavioral techniques yielding a mean score of 7.2 on the VAS.

Details were not collected concerning current or past prescription medications used by the respondents. The complexity of multiple possible medications, varying doses, polypharmacy and long duration of therapy meant that collecting this information and correlating it with the behavioral techniques was deemed impractical. Nearly all respondents were currently using prescription medications for their narcoleptic symptoms and they were asked to compare their experience of the effectiveness of medications with behavioral tactics in general using the VAS. The mean VAS score was 5.3 when asked to

compare a global impression of behavioral tactics relative to optimized prescription medications. Several participants commented that behavioral techniques were previously of greater importance prior to starting sodium oxybate.

## Discussion

A wide variety of behavioral tactics were endorsed as useful for the management of EDS in this population. Physical activity in the form of walking around was the most cited tactic. This finding supports Broughton and Murray's observations that narcoleptic patients rely on physical stimulation to manage symptoms. These data indicate that persons with narcolepsy dealing with EDS use physical activity to address EDS with napping as a second choice. Standing up and walking around in a work or school environment may be more socially acceptable and convenient than taking a nap. Several factors including employment or school schedule likely dictate how often a person can manage EDS with napping. One respondent commented that once retired he could at last take scheduled naps making this self-management tactic more feasible. Conceivably patients select a specific behavioral technique based on their circumstances. Which raises a key question - can time be taken for a planned nap? These data suggest that the respondents' circumstances more often were conducive to walking around.

Respondents commented that they valued behavioral techniques as a means to augment prescription medication. The degree to which self-management tactics could allow for reductions in medication dose or extend the dosing intervals is not known. Having confidence in a variety of coping strategies may enhance a patient's sense of control over EDS and increase self-esteem. Accordingly patients should be encouraged to try behavioral tactics as part of a comprehensive treatment [6]. However, in order to counsel patients adequately, health care providers must have familiarity with self-management techniques [3].

This study had several shortcomings. The diagnosis of narcolepsy was based on patient self-report. In the interest of keeping the survey brief, specific data about the prescription agents, doses, and duration of prescription medication use was not collected. Comparing various medications, combinations of agents, doses and dosing intervals was impractical. Data are not available to compare the efficacy of specific behavioral techniques to specific prescription medications. Numerous patients volunteered that self-management techniques had relatively more value before they were started on medications, specifically sodium oxybate. The survey did not seek to assess if particular techniques were favored in any particular setting or time of day.

The study design solicited input concerning behavioral techniques for EDS with the assumption that subjects had already awakened for the day and were struggling to optimize alertness. The questions did not seek to address the scenario where a patient is regaining alertness after the primary nocturnal sleep episode or a nap. Different tools, such as alarm clocks and vibrating devices, may be used in this setting. Hot showers and baths were included in this survey although when endorsed by respondents it was unclear if these were utilized to prevent drowsiness or regain alertness.

## Conclusions

This project sought to solicit the perception of persons who identify as having narcolepsy regarding self-management techniques for EDS. Walking around and naps were identified as the most commonly used self-management options. Relatively few patients recalled being encouraged by health care providers to supplement prescription approaches with self-management strategies. Subsequent investigations should be undertaken to generate more data about the relative efficacy, timing and application so that these techniques can be optimized for persons with narcolepsy.

## Acknowledgement

The authors wish to thank the leaders and members of the Narcolepsy Network for their interest and invaluable assistance with this study.

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