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## **Behavioral Sleep Medicine Services for Hypersomnia Disorders - A survey study**

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## Abstract

Patients with hypersomnia disorders (HD) suffer from debilitating symptoms that result in reduced functioning, depression, anxiety, and overall worse quality of life. Little is known about the need and desire of this population to utilize Behavioral Sleep Medicine (BSM) interventions that focus on psychosocial functioning and quality of life, and there have been limited attempts to develop such interventions. The purpose of this survey study was to gather patient-centered data on engagement in pharmacological and non-pharmacological interventions, the psychosocial impact of HD symptoms on quality of life and mental health, and potential interest in BSM services, such as cognitive behavioral therapy, mindfulness/yoga, and support groups. We obtained responses from 371 individuals with HD (65.2% narcolepsy and 34.8% idiopathic hypersomnia) to an internet-based survey. Overall, HD patients reported engagement in pharmacological and non-pharmacological interventions, with narcolepsy patients reporting more perceived effectiveness than those with idiopathic hypersomnia. In addition, HD patients reported a strong negative impact on psychosocial functioning, with elevations in depression and anxiety symptoms along with significant impact on functioning and quality of life. The majority (71.7-85.5%) voiced at least some interest in BSM services. These data suggest that there is substantial interest and need for BSM services that focus on assessment and treatment of psychosocial functioning related to HD.

## Introduction

Hypersomnia Disorders (HD) of central origin includes narcolepsy and idiopathic hypersomnia (also called hypersomnolence disorder). These disorders share the core feature of excessive daytime sleepiness (EDS) that occurs on a frequent and persistent basis despite adequate total sleep time and are not attributable to other causes (American Psychiatric Association, 2013). Currently, there is no cure for HD and thus the goal of treatment is symptomatic control, primarily targeting the symptom of EDS (Guilleminault & Cao, 2011; Morgenthaler et al., 2007). Pharmacological approaches are considered the first line treatment. Practice parameters for the treatment of HD by the American Academy of Sleep Medicine concluded that modafinil, amphetamine, methamphetamine, dextroamphetamine, and methylphenidate have sufficient evidence for effectiveness and are appropriate for use in treatment of EDS in HD (Morgenthaler et al., 2007).

In addition to pharmacotherapy, non-pharmacological strategies are commonly used to manage EDS, either as an adjunct to medication or as an alternative treatment. As medications alone may not completely resolve EDS, less than 15% of patients with narcolepsy rely on medications alone (Alaia, 1992) and up to 54% of these patients rely exclusively on behavioral strategies (Bruck & Broughton, 2001; Cohen, Nehring, & Cloninger, 1996; Daniels, King, Smith, & Shneerson, 2001; Rogers, 1984). Common behavioral approaches that are used by patients to manage EDS include scheduled daytime naps, sleep hygiene, dietary manipulations, and physical activity (Cohen et al., 1996; Conroy, Novick, & Swanson, 2012). Patients with narcolepsy also identified environmental manipulations (e.g., avoid hot rooms, keep room cool, seek fresh air),

engagement or disengagement in activities (e.g., be active in conversations, avoid ‘boring’ events, restrict evening events) and different physical (e.g., pinch self, clench teeth) and emotional techniques (e.g., avoid emotional experiences, excitement) for management of symptoms (Cohen et al., 1996). However, there are limited data on HD patient’s perceived ratings of effectiveness and where they learn these non-pharmacological interventions for EDS.

Although EDS is the primary symptom of HD, the consequences of these conditions extend beyond the effects of sleepiness and the deleterious impact on psychosocial factors and quality of life has been well documented (Bruck & Broughton, 2001; Daniels et al., 2001; Dodel et al., 2007; Jennum, Ibsen, Avlund, & Kjellberg, 2014; Ozaki et al., 2012; Rogers, 1984; Vignatelli et al., 2004; Vignatelli, Plazzi, Peschechera, Delaj, & D’Alessandro, 2011). Patients with HD have more educational problems, behavioral problems, show higher rates of depression, anxiety, experience more challenges at work, and are more prone to driving accidents (Daniels et al., 2001; Dauvilliers, Lopez, Ohayon, & Bayard, 2013; Dodel et al., 2007; Douglas, 1998; Stores, Montgomery, & Wiggs, 2006; Vernet & Arnulf, 2009). While treatments for HD have been aimed at improving EDS, there is virtually no literature on treatments aimed at addressing emotional or psychosocial functioning related to EDS. In a recent systematic review evaluating the literature on non-pharmacological strategies for narcolepsy (Neikrug & Ong, in press), we observed that the majority of studies were conducted over 14-39 years ago and only one study assessed for psychiatric symptoms as an outcome and no study evaluated quality of life. We also found no study of cognitive strategies, educational interventions, or multi-component therapy that address psychosocial

functioning or coping with the impact of HD symptoms. Instead, the majority of research has focused on the effect of behavioral strategies to reduce EDS (e.g., scheduled daytime naps). Given that patients with HD carry a heavy disease burden and chronic EDS has such a deleterious effect on the quality of life, there is a major gap in the literature on formal interventions aimed at improving psychosocial functioning and quality of life in HD patients.

Behavioral sleep medicine (BSM) is a rising specialty that focuses on cognitive, behavioral and emotion-focused approaches in the prevention and treatment of sleep disorders. Within BSM, cognitive-behavioral therapy for insomnia (CBTI) has gained prominence as an empirically supported treatment for chronic insomnia (Merrigan, Buysse, Bird, & Livingston, 2013). However, far less attention has been given to the systematic development and testing of formal BSM interventions aimed at disorders of chronic EDS. Currently, there is no specific data to indicate that BSM services are needed for patients with HD and it is not known if patients with HD would be interested in BSM services, such as a cognitive-behavior therapy, to aid in symptom management and psychosocial functioning.

The aim of this study was to evaluate the concept viability of developing formal BSM services for patients with HD. Using a population-based survey, we sought to gather patient-centered data to characterize patient engagement in pharmacological and non-pharmacological interventions, the psychosocial impact of HD, and patient interest in formal BSM services, such as cognitive behavioral therapy, mindfulness/yoga, and support groups. We hypothesized that: 1) Both pharmacological and non-pharmacological approaches are highly used by HD patients, 2) HD patients experience

elevations on symptoms of depression and anxiety, and 3) HD patients would endorse interest in formal BSM services, including CBT, support groups, and mindfulness-based approaches.

## Methods

### *Design Considerations*

This study was initiated to serve as a starting point for developing a BSM intervention for patients with HD. Following Stage Ia of developing behavioral interventions, where the focus is on developing the elements needed to test the intervention (Rounsaville, Carroll, & Onken, 2001), the purpose of this study was to examine the concept viability of delivering BSM services to patients with HD. Therefore, the overarching goal was to gather data on the *need* for cognitive and behavioral interventions, the potential treatment *targets*, and patient *acceptability* of these approaches. We elected to use a population-based survey design to optimize generalizability and enhance representation of the population of people with HD. To facilitate honest responses to potentially sensitive information (e.g., mental health symptoms), we did not collect identifiable information (i.e., name, location), maintaining patient anonymity. These findings are intended to inform further treatment development activities (e.g., development of a treatment manual) with the eventual goal of conducting a pragmatic clinical trial. We have outlined our process model of treatment development and testing in Figure 1.

### *Survey Design*

The survey was developed in multiple phases by the authors (ABN, JCO, and MRC) and was guided by the previous surveys conducted in narcolepsy patients (Cohen

et al., 1996; Rogers, 1984). The survey was designed to be completed in less than 10-minutes and therefore mainly included forced-choice multiple response questions, closed ended questions, and rating scales. The survey included a total of 33 multi-itemed questions divided into several sections that asked about: diagnosis and disease symptoms, medication use and perceived effectiveness, behaviors and non-drug strategies for managing symptoms and their perceived effectiveness, mental health history, interest and experience in non-pharmacological interventions (e.g., cognitive-behavioral therapies, mindfulness meditation, yoga, and support groups), and demographics. Each section was presented with a brief explanation regarding the section. This was an internet-based survey that was designed and distributed using SurveyMonkey©.

#### *Survey Procedures and Participants*

To identify patients with HD we partnered with Wake Up Narcolepsy, a patient-run organization. The organization distributed the SurveyMonkey© link to members on their email listserv. The survey was open for 29 days between August 8 and September 5, 2014. Two email notifications were sent by the organizations to their members the first on August 8 and the second on August 29. The survey was anonymous in order to maximize honest reporting. Survey respondents were provided with a brief written explanation of the survey and its purposes and all respondents had to agree to start the survey prior to seeing any additional content. This study was reviewed and approved by the Institutional Review Board of Rush University Medical Center as an exempt study, as no protected health information or identifiers were collected.

For this study, we included participants who were at least 17 years of age and self-reported a diagnosis of narcolepsy (Type I or Type II) or idiopathic hypersomnia.



Descriptive statistics including frequencies, means and standard deviations were generated for general description of the data. Independent sample t-tests and Chi Square tests were conducted as post-hoc analyses to explore potential differences between diagnostic groups and gender. Statistical analyses were performed using SPSS for Mac, version 21.0 (IBM Corp., 2012, Armonk, NY).

### Results

A total of 518 survey responses were recorded. First, we screened the dataset for incomplete or unreliable data. We excluded 3 duplicate responses (i.e., responses were identical with either exact time stamp or few minutes apart). Additionally, we excluded 50 respondents who did not respond past the first 4 survey questions (questions 1-3 included agreement to participate, diagnosis, and types of non-pharmacological strategies utilized) as no data pertaining to our hypotheses were included in these questions. Second, from the remaining 465 survey responses, we excluded individuals who did not meet our study criteria. We removed 38 responses that identified themselves as responding on behalf of someone else with either narcolepsy or idiopathic hypersomnia. We excluded one respondent who did not identify a diagnosis but completed the survey, seven participants that endorsed both having idiopathic hypersomnia and narcolepsy, and 20 participants who reported not yet receiving a diagnosis. Finally, we excluded 28 respondents who were under the age of 17 or did not report age. The remaining 371 respondents were included in the analyses. The majority (86.3%) identified as females and 12.7% as males. Mean age was  $37.1 \pm 11.1$  (Range: 17-72). Complete demographics are provided in Table 1.

#### *Patient Profile*

Of the 371 respondents, 65.2% percent identified as having narcolepsy and 34.8% as having idiopathic hypersomnia. As expected, 97.6% of the respondents reported currently experiencing significant EDS. Also expected is that cataplexy was reported by 66.1% of those with narcolepsy and none of those with idiopathic hypersomnia. As seen in Table 2, those who identified as having narcolepsy reported more narcolepsy-related symptoms compared to those who identified as having idiopathic hypersomnia, suggesting the diagnosis was reported accurately and honestly. The mean age of symptoms onset was  $17.9 \pm 9.3$  (Range: 0-57).

#### *Pharmacological Treatment*

The majority of respondents (83.3%) reported the use of medication to manage symptoms (Table 3). Use of stimulants were endorsed by 48%, modafinil/armodafinil were endorsed by 42%, sodium oxybate/ $\gamma$ -hydroxybutyric acid by 21%, and antidepressants were endorsed by 29% of the respondents. There was a significant group difference in the use of sodium oxybate/ $\gamma$ -hydroxybutyric acid which was significantly more utilized by patients with narcolepsy (31% vs. 4%,  $p < 0.001$ ). There were no significant differences between the groups or genders (Table 3). Sixty nine percent of the respondents reported taking the medications daily and only 5% reported using the medication on three or less days per week. Interestingly, 23% of the respondents reported that side effects from the medications have been preventing them from using the medications consistently with no significant differences between groups or gender. Medication effectiveness was rated by the entire sample as  $6.0 \pm 1.8$  on a 0-10 scale (0 being not at all effective and 10 being most effective) and narcolepsy patients rated

medication as more effective compared to those with idiopathic hypersomnia ( $6.2 \pm 1.7$  vs.  $5.4 \pm 1.9$ ,  $p < 0.001$ ).

#### *Non-pharmacological strategies*

Respondents endorsed multiple non-pharmacological strategies/behaviors to help manage symptoms of the disease (Table 4a). Over 90% of the respondents reported using more than 1 strategy to manage symptoms, and daytime naps, scheduled nocturnal sleep, and caffeine emerged as the top 3 strategies. Daytime napping was the strategy most commonly endorsed (86%), followed by scheduled nocturnal sleep (i.e., bedtime and wake uptime) (76%), and caffeine (76%). Participants also reported use of exercise (57%), diet (50%), temperature manipulations (42%), chewing gum (30%), nicotine (23%), mindfulness (21%), and yoga (18%). Use of diet as a strategy to manage symptoms was more commonly reported by patients with narcolepsy compared to patients with idiopathic hypersomnia (55% vs. 40%,  $p = 0.004$ ). Other strategies that were reported by <5% of the respondents included Tai Chi, acupuncture, light therapy, energy drinks, poking themselves, flicking a rubber band on wrist, continual walking, eating ice, aroma therapy, use of different vitamins (e.g., B12, Vitamin C) and food supplements (e.g., iron, ginseng), music and brainwave apps, cognitive training, and massage therapy. Only 3.1% of the respondents reported that they do not use any non-pharmacological strategies. No gender differences were found in reported strategies.

While these strategies were widely used, the perceived effectiveness was generally rated poorly (Table 4b). Daytime napping received the highest rating of effectiveness of  $4.3 \pm 2.8$  out of a 0-10 scale (0 being not at all effective and 10 being most effective). Daytime napping was followed by scheduled sleep and diet manipulation with

a rated effectiveness of 4.0. Caffeine, nicotine, and exercise followed with ratings <4.0. We found that there were significant differences in these ratings between the diagnostic groups. Except for nicotine, patients with narcolepsy reported significant higher effectiveness for all strategies (Table 4b).

Respondents were also asked to endorse different ways in which they have learned about non-pharmacological strategies. Most responded learning strategies from non-professional sources (78% by trial and error, 44% by Internet, 38% from other patients, and 25% through patient-related organization). Nonetheless, 33% reported that they were educated about non-pharmacological strategies by a sleep specialist and 24% by their primary physician.

#### *Mental Health and Psychosocial Impact*

The respondents reported a negative impact on functioning and mental health. In particular, cardinal symptoms of depression and anxiety were endorsed by 61-91% of individuals (Table 5) and only 4 participants with narcolepsy (1%) reported that they never experienced mood or anxiety symptoms as a result of their disease symptoms. Referrals to mental health specialists were also common and reported by 46% of the respondents. The effectiveness of mental health interventions was rated as  $5.0 \pm 3.2$  on a 0-10 scale (0 being not at all effective and 10 being most effective). There were no group or gender differences in referrals to mental health provider, or in effectiveness rating.

Respondents reported that the disease symptoms have had a significant impact on their quality of life. When asked to rate the extent to which they have experienced difficulties in work/school, family relationships, and social relationship on a 0-10 scale (0 being no difficulties and 10 being extreme difficulties), respondents rated experienced

difficulties generally high: difficulties in work and school were rated  $8.4\pm 1.8$ , difficulties with family relationships were rated  $7.3\pm 2.6$ , difficulties in social relationship were rated  $7.8\pm 2.4$ . Additionally, participants reported that avoiding situations due to the symptoms of the disease resulted in significant difficulties in their lives (rated  $7.2\pm 2.5$ ). There were no group or gender differences in these variables.

### *Interest in BSM services*

The respondents endorsed overall high levels of interest in formal non-pharmacological treatments that could be delivered as BSM services. The majority (86%) voiced at least some interest in support groups, nearly two thirds (74%) endorsed interest in CBT, and 72% endorsed interest in mindfulness/yoga techniques (Table 6). When asked for the reasons for low or no interest in these services those respondents endorsed questionable effectiveness, having no time, and being satisfied with current medication regimen. Participants were also asked to identify the type of professional they would feel more comfortable with for learning non-pharmacological strategies. The majority (62%) indicated a preference for a BSM provider (i.e., psychologist, nurse, or psychiatrist with training in both mental health and sleep disorders), 23% preferred a physician specialized in sleep, 4% identified a mental health provider (i.e., psychologist, psychiatrist, or social worker), 4% identified their primary care provider, and 1% identified their nurse.

## Discussion

The main goal of this study was to gather patient-centered data on the importance, need, and interest in formal non-pharmacological BSM services for patients with HD. First, patient engagement for both pharmacological and non-pharmacological

interventions was high. Eighty three percent of respondents reported the use of medication to manage HD symptoms with the most common medications being stimulants, followed by modafinil/armodafinil. Furthermore, these medications were perceived to be relatively effective with an average rating of 6 out of 10 and 69% reported daily use, which is considerably higher than previous reports among narcolepsy patients (Rogers, Aldrich, Berrios, & Rosenberg, 1997; Rogers, Aldrich, & Lin, 2001). Patients with idiopathic hypersomnia reported lower (6.2 vs. 5.4) effectiveness scores for medications. These findings indicate that HD patients are generally engaged in pharmacotherapy and perceive these as relatively effective, but with more perceived effectiveness by patients with narcolepsy.

There was also high patient engagement for non-pharmacological interventions to manage EDS, with over 90% of the respondents reported using at least one non-pharmacological strategy, such as daytime napping, caffeine, or a sleep schedule. However, these strategies were perceived to have low to moderate effectiveness (ranging from 1.9 to 4.3 out of 10) and patients with idiopathic hypersomnia consistently provided lower effectiveness rating to all strategies except for nicotine use. Low effectiveness rating could be due to limited professional supervision or guidance for using these strategies. Only 33% reported that they learned these strategies from a sleep specialist and 78% reported that they learned these strategies through trial and error, 44% via the Internet, and 38% from other patients. Given the minimal professional oversight, it is unclear if these strategies were implemented correctly or systematically, which could amplify frustration with using these non-pharmacological techniques and cause patients to abandon these strategies prematurely. It would seem that formal guidance from a sleep

physician or a BSM clinician is needed to evaluate the effectiveness of these behavioral strategies for managing EDS.

Consistent with previous research, respondents reported high elevations on mental health symptoms and impaired psychosocial functioning. Symptoms of depression and anxiety were extremely common, ranging from 61% to 91% with no significant differences between patients with narcolepsy and idiopathic hypersomnia. The most prominent symptoms endorsed were difficulty with concentration (91%), irritability (87%), lost of interest (81%), and sad mood (81%). Furthermore, referral to a mental health professional had only moderate effectiveness, rated as a 5 out of 10. When asked about interest in BSM services that could address these mental health symptoms, patients were generally enthusiastic, with 62% of patients endorsing a preference to work with a BSM provider. In terms of the type of service that could be used to address these psychosocial needs, 86% of patients expressed at least some interest in support groups, 74% were interested in CBT, and 72% were interested in mindfulness/yoga. These findings indicate that despite engagement in pharmacological and non-pharmacological treatments for EDS, both narcolepsy and idiopathic hypersomnia patients have severe impairments in psychosocial functioning. Furthermore, they are enthusiastic about services such as support groups, CBT, and mindfulness-based approaches that could be used to improve psychosocial functioning and aid in coping with HD. The majority of patients also favor a BSM provider to deliver these services.

#### *Study Limitations*

There are some limitations to this study. This was a population-based, anonymous, Internet survey study and therefore we were unable to confirm accuracy of the diagnoses

or responses. Additionally, the survey was non-standardized and was not assessed for psychometric validity/reliability. While there were several standardized questionnaires that could have been used, these would have made the assessment significantly longer. We intentionally designed this survey to be brief to minimize burden and enhance participation since there was no compensation offered for completing the survey. It is possible that the lack of standardized assessments or a trained interviewer may have resulted in biased or inaccurate responses. Additionally, this study was not designed for group comparisons (by diagnosis and by gender) and due to the post-hoc and exploratory nature of these analyses further hypothesis-driven research using more rigorous methods should be conducted to confirm group differences observed in this study. Nonetheless, the aim of this preliminary study was to evaluate the concept viability of BSM services for patients with HD. As such, we felt that a survey study would allow us to gather data using a large sample at this stage of treatment development with future studies providing more rigorous testing and precision (see Figure 1).

#### *BSM Services in the Management of HD: Clinical Implications*

The findings from this survey point towards several possibilities for BSM services to be delivered to patients with HD. One possibility is that a BSM clinician could provide formal guidance and oversight on behavioral interventions, such as scheduled naps and scheduled nighttime sleep to help manage EDS symptoms. Prescribed scheduled naps have been shown to be effectiveness in improving alertness (Billiard, 1976; Guilleminault, Stoohs, & Clerk, 1993; Helmus et al., 1997; Mullington & Broughton, 1993, 1994; Roehrs et al., 1986; Rogers & Aldrich, 1993; Rogers et al., 2001), especially for those who report high baseline levels of sleepiness (Rogers & Aldrich,



1993; Rogers et al., 2001). Some patients might benefit from multiple short naps throughout the day (Godbout & Montplaisir, 1986; Mullington & Broughton, 1993; Rogers & Aldrich, 1993) while others might benefit from a single longer nap (Helmus et al., 1997). Scheduled naps can also be combined with a structured and regular bedtime schedule, as tested by Rogers et al. (2001) to address nocturnal sleep disturbances, which were the second most commonly reported symptom in our survey. The use of daytime sleep/wake diaries that specifically track daytime napping along with ratings systems of sleepiness/alertness could help determine specific napping and sleep schedules. A second possibility is to develop interventions featuring education and cognitive skills targeting the mood/anxiety symptoms and psychosocial impairment that were revealed in this survey study. Approaches such as Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 1999) or mindfulness-based therapies (e.g., Ong, Ulmer, & Manber, 2012) may be appropriate to help patients shift from control of symptoms to management of symptoms while focusing on values and desired functioning. Other techniques such as motivational interviewing, behavioral experiments, and relapse prevention could also be delivered by a BSM clinician (Kaplan & Harvey, 2009). A third possibility is to combine these interventions into a formal multicomponent treatment package, similar to cognitive-behavior therapy for insomnia. At this time, there is insufficient evidence to consider these potential BSM services as an alternative to pharmacotherapy. Instead, BSM clinicians should work together with a physician to optimize multidisciplinary care.

### *Conclusion*

These findings support the concept viability for BSM services as an adjunctive or complementary treatment with pharmacotherapy for patients with HD. In particular,

there is an unmet need to improve emotional and psychosocial functioning related to HD and patients reported enthusiasm for support groups, CBT, and mindfulness that are specifically aimed at improving emotional and psychosocial functioning. In addition, BSM clinicians can provide formal guidance or supervision for implementing behavioral strategies to manage EDS. Combining BSM services with pharmacotherapy could provide comprehensive care for patients with HD and significantly improve health-related quality of life.

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