CHAPTER

5

CBT-I for patients with hypersomnia disorders

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Introduction

Normal levels of alertness are necessary for humans to engage in physical, mental, and social activities. Difficulty maintaining alertness or wakefulness due to excessive daytime sleepiness (EDS) is experienced by 27.8% of the general population (Ohayon, Dauvilliers, & Reynolds, 2012). In most cases, EDS is a symptom due to insufficient sleep quantity, sleep quality, or circadian dysregulation. When EDS is persistent and occurs despite adequate sleep and circadian timing, it is considered a central disorder of hypersomnolence (CDH) (American Academy of Sleep Medicine, 2014). Among CDH, the two most common conditions are narcolepsy and idiopathic hypersomnia (IH). Since these two conditions share the cardinal feature of persistent EDS with similar effects on daytime functioning, they will be referred to as chronic hypersomnia (CH) here. Other CDH conditions such as Kleine-Levin syndrome have different features, such as intermittent episodes of EDS, or have a different etiology (e.g., due to other medical or psychiatric condition). Therefore, the focus of this chapter will be on CH and cognitive-behavioral approaches to managing these conditions. The first section provides an overview of CH, including diagnosis, pathophysiology, epidemiology, with an emphasis on the psychosocial aspects of CH. Next, treatments are discussed, including current pharmacological treatments and the cognitive and behavioral strategies that can be used to help manage CH symptoms and improve

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health-related quality of life. Finally, we provide suggestions for future directions in managing CH with cognitive-behavior therapy.

A primer of chronic hypersomnia

Diagnosis

Narcolepsy is the most well-known CH and is characterized by EDS that occurs on a frequent (≥3 times per week) and persistent (≥3 months) basis despite adequate total sleep time (American Psychiatric Association, 2013). Other symptoms include nocturnal sleep fragmentation, hypnogogic hallucinations, sleep paralysis, and vivid dreams, which appear to involve an intrusion of the REM state into wakefulness (Scammell, 2015). Narcolepsy can be further distinguished into subtypes based on clinical evidence of cataplexy, which is the sudden loss of muscle tone often in response to strong emotion, such as laughter, surprise, excitement, anger, or happiness (Krahn, Lymp, Moore, Slocumb, & Silber, 2005). This loss of muscle tone can occur in the jaw, hands, or knees, and result in slurred speech, or in some cases, complete paralysis (Won et al., 2014). Those who show signs of cataplexy are classified as Narcolepsy Type 1 (NT1) while those without cataplexy are categorized as Narcolepsy Type 2 (NT2).

In addition to clinical symptoms, diagnosis of narcolepsy requires laboratory testing through overnight polysomnography (PSG) followed by a next-day multiple sleep latency test (MSLT). A sleep-onset rapid eye movement period (SOREMP) of less than 15 min on the overnight PSG and/or a mean sleep latency of less than 8 min on the MSLT is needed to meet diagnostic criteria for narcolepsy. If available, a hypocretin assay derived from the Cerebrospinal Fluid (CSF) can be used to determine hypocretin levels, where low hypocretin-1 is consistent with a diagnosis of narcolepsy. A value of 110 pg/mL or less than one-third of the normative values on a standardized assay qualifies as a hypocretin deficiency, warranting the diagnosis for Narcolepsy Type 1 (American Academy of Sleep Medicine, 2014).

Similar to narcolepsy, IH shares the core feature of EDS that is present for at least 3 months and is not due to other causes. In addition, people with IH often report sleep inertia, sometimes referred to as "sleep drunkenness," which is characterized by significant difficulty rousing or feeling alert upon awakening. Unlike NT1, people with IH do not report cataplexy and there is an absence of REM-related symptoms, such as hypnogogic hallucinations and sleep paralysis. Furthermore, there is an absence of SOREM on the PSG and MSLT (Bassetti & Aldrich, 1997).

About 30% of individuals with IH also report long nocturnal sleep time (≥10 h) and many people with IH also take long unrefreshing naps (≥60 min), which are atypical of people with narcolepsy (American Academy of Sleep Medicine, 2014). Moreover, people with IH can exhibit a wide range of symptoms such as irresistible daytime napping, difficulty waking in the morning, or nonrestorative sleep after 9 h (Trotti, 2020), making it difficult to determine differential diagnosis from other hypersomnolence disorders such as NT2 and insufficient sleep syndrome (Trotti, 2017).

Recently, there has been a proposal to re-classify CH (Fronczek et al., 2020). Based upon updated findings that IH with long sleep time have distinct features, Fronczek et al. (2020) propose that IH with long sleep time be considered a separate condition. They also propose "lumping" NT2 and IH without long sleep time into a new diagnosis called "narcolepsy spectrum disorder" due to similarities in phenotype and the poor reliability of the MSLT in differentiating NT2 from IH. Finally, they propose to retain NT1 as a diagnostic category given the diagnostic reliability and validity of identifying NT1 and the well-characterized pathophysiology of NT1.

Pathophysiology

Relative to other forms of CH, NT1 has the most established pathophysiological model with a deficiency in hypocretin, a neuropeptide produced in the lateral hypothalamus that contributes to wakefulness and arousal (Ebrahim, Howard, Kopelman, Sharief, & Williams, 2002). Specifically, several studies have demonstrated the destruction of hypocretin (orexin) producing cells in the hypothalamus leading to a deficiency in the hypocretin (Nishino, Ripley, Overeem, Lammers, & Mignot, 2000). This has led some to consider narcolepsy a "hypocretin deficiency syndrome." In addition, there is evidence of a genetic predisposition with the HLA-DR and HLA-DQ alleles. In NT2, hypocretin levels are generally normal. Although there are some cases of hypocretin deficiency in NT2, the findings are not as consistent compared to NT1 and might indicate a different progression in the disease course. About 20% of people who are initially diagnosed with NT2 ultimately develop hypocretin deficiency leading to a diagnosis change to NT1 (Han et al., 2014). Unfortunately, very little is known about the etiology of IH. A survey study showed that 34% of patients with IH reported a family history of excessive daytime sleepiness suggesting a possible genetic influence, though it has not been identified (Anderson, Pilsworth, Sharples, Smith, & Shneerson, 2007).

Epidemiology

Both narcolepsy and IH are considered rare diseases with prevalence estimates of around 25 to 50 people per 100,000, or about 0.025% to 0.05% of the general population (Longstreth Jr., Koepsell, Ton, Hendrickson, & van Belle, 2007). One study that examined the US health care claims database for the years 2008 through 2010 reported that 0.08% of enrolled patients were diagnosed with narcolepsy, including 0.014% with NT1 and 0.065% with NT2 (Scheer et al., 2019). Unfortunately, the prevalence of IH remains unknown with a lack of comprehensive studies investigating the prevalence of IH in the general population (Billiard & Dauvilliers, 2001). However, a study investigating medical/prescription claims to assess the prevalence of IH found that 7.7 per 100,000 people in 2013 were diagnosed with IH and 10.3 per 100,000 people in 2016, suggesting an increasing number of people receiving treatment (Hess et al., 2018).

One challenge with estimating the prevalence of CH is that many people with CH remain undiagnosed, are misdiagnosed, and many have a protracted time between the onset of symptoms and the confirmation of a CH diagnosis. One study found that the median time from the onset of narcolepsy symptoms to diagnosis was 22 months with 18% of the sample reporting at least 5 years between the onset of symptoms and diagnosis (Carter, Acebo, & Kim, 2014). Additionally, 60% of patients in this study had been misdiagnosed with a different disorder, such as depression, insomnia, and sleep apnea, and at least half of the patients required evaluation by multiple providers.

With regards to age, the prevalence of narcolepsy was highest in the 21–30 age group, and incidence was highest in people in their late teens to early twenties (Scheer et al., 2019). Typically, the first symptom to occur is EDS, which emerges between age 15 and 25. With narcolepsy, other symptoms such as cataplexy and other REM-related symptoms typically emerge after the onset of EDS. Therefore, the likely progression is the emergence of symptoms in adolescence to early adulthood, but diagnosis is often not confirmed until the mid to late 20s or early 30s.

Studies have revealed inconsistent findings with regard to gender distribution (Hale, Guan, & Emanuele, 2016). One longitudinal study examining the incidence of narcolepsy between 1960 and 1989 in Minnesota found no significant differences between gender with an incidence rate of 1.72 per 100,000 for men and 1.05 per 100,000 for women (Silber, Krahn, Olson, & Pankratz, 2002). However, a broader study examining the US Health Care Claims database from 2008 to 2010 (Scheer et al., 2019) found a higher prevalence of narcolepsy in females (91.8 per 100,000) compared to males (65.8 per 100,000). These discrepant findings

could indicate that females are more likely to access healthcare and seek diagnosis and treatment for narcolepsy symptoms compared to males.

Psychosocial aspects of hypersomnia

The symptoms of CH have a profound impact on daily functioning, leading to a significant impact on health-related quality of life (HRQoL). In studies across different countries around the world (Daniels, King, Smith, & Shneerson, 2001; David, Constantino, dos Santos, & Paiva, 2012; Dodel et al., 2007; Vignatelli et al., 2004; Vignatelli, Plazzi, Peschechera, Delaj, & D'Alessandro, 2011), CH patients consistently reported poor HRQoL, especially in terms of lack of vitality/energy and problems with carrying out their daily activities or role. A mixed-methods study examining how narcolepsy symptoms impact quality of life found that the constancy of EDS and the unpredictability of other symptoms, such as cataplexy, had the most negative impact on HRQoL (Ong, Fox, Brower, Mazurek, & Moore, 2020). As an example, one participant described significant anxiety when approaching an area on campus where a previous cataplectic attack had occurred and began to avoid that area. When asked how narcolepsy impacted their daily lives, participants reported four major domains (Ong, Fox, et al., 2020). First, patients struggled with self-esteem and self-efficacy. Some described that they were ashamed of having narcolepsy and had low self-worth and others described a loss of productivity and limitations in their ability to participate in activities at a level they were accustomed to in the past. People with narcolepsy also reported the stigma of being diagnosed with narcolepsy, noting that popular media often mock people with narcolepsy through their depiction in movie characters and cartoons and the general public does not recognize it as a serious condition. Second, the cognitive impairment or "brain fog" associated with narcolepsy had detrimental effects on the ability to accomplish tasks and often had difficulty staying organized. Third, the symptoms had a significant impact on social functioning and interpersonal relationships. Patients reported that the limitations caused by their symptoms were detrimental to maintaining social relationships (Ong, Fox, et al., 2020). Many felt that their friends perceived them as unreliable and others reported being unable to travel or not being able to be active in social situations due to fatigue and EDS. Some patients also reported that narcolepsy impacted their decision to have children due to concerns that narcolepsy symptoms might compromise their ability to be a caretaker. Another study found that 72% of patients with narcolepsy reported interpersonal distress (marital and family conflicts) with 20% identifying narcolepsy as the reason for divorce or separation

(Kales et al., 1982). Finally, some people with narcolepsy have changed jobs or abandoned career aspirations due to the impact of narcolepsy symptoms (Ong, Fox, et al., 2020).

These challenges in psychosocial functioning are associated with a greater risk for developing comorbid mood disorders, anxiety disorders, and substance use disorders related to self-medication of stimulants (Ford & Kamerow, 1989; Ohayon, 2013; Ohayon et al., 2012). People with narcolepsy (PWN) report elevated symptoms of depression and anxiety (Dauvilliers et al., 2009; Flores, Villa, Black, Chervin, & Witt, 2016; Neikrug, Crawford, & Ong, 2017) that are two to three times the rate of mood and anxiety disorders and significantly higher work absenteeism compared to matched controls (Flores et al., 2016). Furthermore, PWN uses twice the amount of medications for comorbid medical and psychiatric conditions compared to matched controls (Black et al., 2014) with 37% of PWN taking antidepressant medications (Ohayon, 2013). One study also found that poor HRQoL is present even when treated with pharmacotherapy (Dauvilliers et al., 2009). Collectively, these studies indicate that poor psychosocial functioning is a significant problem that is not adequately addressed with current therapies (see Fig. 1).

Unfortunately, much less attention has been given to investigating the psychosocial aspects of IH specifically. Studies that have included IH with narcolepsy (e.g., (Neikrug et al., 2017; Ozaki et al., 2012) have generally found deficits in HRQoL, which are comparable to those found in narcolepsy. There is a clear need for further research in examining specific aspects of HRQoL associated with IH.

Treatments for chronic hypersomnia

Pharmacological treatments

To date, no cure has been discovered for either narcolepsy or IH. Pharmacotherapy is the standard treatment for CH and is primarily targeted at EDS, with some medications also targeting other symptoms such as cataplexy and consolidation of nighttime sleep (see Table 1). Traditionally, stimulants have been used as the first-line treatment for EDS given their wake-promoting effects. However, these medications are tightly regulated and can produce undesirable side effects such as anxiety or appetite suppression. Stimulants are also contraindicated in patients with hypertension. One study showed that 60% of patients taking stimulants for CH reported side effects, and 30% reporting that these side effects were treatment-limiting (Thakrar et al., 2018). The same study found that combination treatment was associated with fewer side effects when compared with monotherapy. In addition to stimulants, newer medications for CH

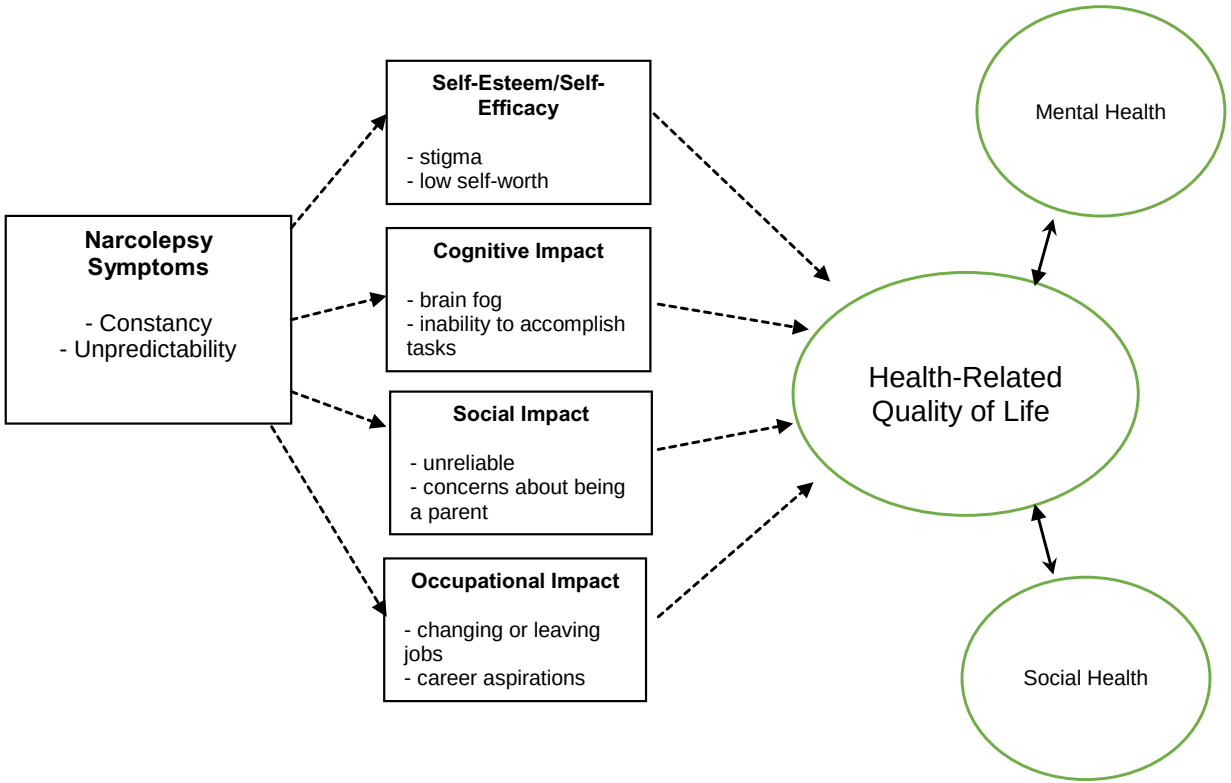

FIG. 1 Psychosocial model for the impact of narcolepsy on health-related quality of life.

TABLE 1 Pharmacotherapy for chronic hypersomnia.

Drug	Class	Indication
Pitolisant	Histamine inverse agonists	EDS & cataplexy
Sodium oxybate	CNS depressant	EDS & cataplexy
Modafinil	Nonamphetamine stimulant	EDS
Armodafinil	Nonamphetamine stimulant	EDS
Dextroamphetamine	Stimulant	EDS
Methylphenidate	Stimulant	EDS
Imipramine	TCA	Cataplexy
Nortriptyline	TCA	Cataplexy
Fluoxetine	SSRI	Cataplexy
Venlafaxine	SNRI	Cataplexy
Selegiline	MAO-B inhibitor	EDS & cataplexy

have included other drug classes. Sodium oxybate is a central nervous depressant that has been shown to reduce cataplexy in addition to reducing EDS. As a result, it has emerged as a standard treatment for narcolepsy, particularly for NT1. Pitolisant is a histamine antagonist/inverse agonist that has demonstrated effectiveness for EDS and cataplexy. In addition, there is low potential for abuse and therefore is currently the only FDA-approved nonscheduled drug for narcolepsy.

Cognitive and behavioral treatments for hypersomnia

Previous studies have found some support for using behavioral strategies to reduce subjectively and objectively measured sleepiness and to improve functional performance (Helmus et al., 1997; Mullington & Broughton, 1993; Rogers, Aldrich, & Lin, 2001). The most common behavioral recommendation for coping with EDS is scheduled daytime naps, whereby the clinician establishes a structure of prescheduled, prophylactic nap periods during the day with the intent of improving alertness and cognitive functioning. One study also examined the impact of adding a consistent nocturnal sleep schedule with or without the scheduled naps (Rogers et al., 2001). In general, these studies found indications that regular scheduled sleep periods can reduce sleepiness and improve some aspects of performance, but the effects were heterogeneous, transient, and often limited to those with more profound EDS despite the use of

stimulant medications. Moreover, these studies included small sample sizes and were relatively short in duration (1 to 2 weeks). Finally, none of these studies evaluated mood or HRQoL so it is unclear if behavioral treatments can improve other patient-reported outcomes. Unfortunately, very little research has been conducted to further test these behavioral strategies since the early 2000s.

A cognitive-behavioral program for hypersomnia

With the increased focus on HRQoL in CH, opportunities are emerging for Behavioral Sleep Medicine to provide services to help people with narcolepsy and IH manage symptoms and improve psychosocial functioning. Recent work has been conducted to develop and test cognitive and behavioral strategies that include components of cognitive-behavior therapy for insomnia (CBT-I) to optimize nighttime sleep, daytime components such as scheduled naps and daytime activities to manage sleepiness and energy throughout the day, and novel strategies for emotion regulation and interpersonal functioning to improve self-efficacy with regards to managing the impact of hypersomnia on HRQoL (see Table 2). Given the heterogeneity of symptoms and intensity across narcolepsy and IH, these techniques are intended to be delivered in modules that allow clinicians to select and customize the techniques based on the patient's symptom profile. Finally, these techniques were designed to be delivered as adjunctive therapy to patients who are receiving standard care for CH. The following sections describe these components that collectively form a novel cognitive-behavior therapy for hypersomnia (CBT-H) program.

Education about hypersomnia

Many patients with CH and their family members are very interested in learning about their condition. However, there are many misconceptions about CH, and some might not have a proper understanding of the condition, the nature of the symptoms, and the potential impact it might have on their functioning and HRQOL. In other cases, patients might have received education from a sleep specialist upon diagnosis of their condition, but other questions arise as their condition progresses or they encounter challenges with their symptoms in new situations. Therefore, assessing the patient's knowledge about their condition, their understanding of treatment options, and their expectations of living with hypersomnia can provide an opportunity to provide education as needed. The level of information should be customized to the appropriate patient demographics (e.g., patient's level of education, living situation). In some cases, having a partner or family member present can be important so that

TABLE 2 Adaptation of CBT-I Components for Hypersomnia.

CBT-I Components	Standard practice	Modifications/Adaptions
Sleep education	3-P model, 2-process model of sleep regulation, sleep stages	– Education about the basics of hypersomnia – Education about treatment options for hypersomnia – Provide resources for further educational opportunities (e.g., patient organizations, online materials)
Sleep restriction	Improve sleep efficiency by limiting time in bed to the amount of time sleeping then expanding slowly as long as sleep efficiency is preserved	– Rather than reducing TIB, the focus is on regulating TIB – Set alarms or reminders for bedtime and wake up time
Stimulus control	Associate bed/bedroom solely as a cue for sleep by eliminating non-sleep activities from the bedroom. Instruction to get out of bed at night if awake >15 min	– No modifications – Not typically needed for hypersomnia patients, since prolonged awakenings are uncommon
Napping/daytime sleep	Discontinue or restrict daytime napping to 30 min	– Use scheduled naps and scheduled activities to manage energy and alertness during the day – Split up the day into smaller segments or "windows" for sleep and activities – Schedules should be customized
Sleep hygiene education	Address daytime habits and sleep environment interfering with sleep	– No modifications

Cognitive therapy	Challenge patient's dysfunctional beliefs interfering with sleep and misconceptions about sleep. Replace/ restructure to more helpful and realistic thoughts about sleep	– Cognitive strategies aimed at improving self-efficacy for managing hypersomnia symptoms – Cognitive strategies aimed at improving self-esteem and self-image related to the stigma of hypersomnia
Mindfulness and acceptance	N/A	– Self-compassion can be used as a tool work with low self-esteem and/or self-efficacy – Active acceptance can help reduce anxiety or depression related to hypersomnia symptoms – Value-based living can help patients identify modifications to activities while still maintaining their core values
Sleep diaries	Establish baseline sleep patterns, track progress, reinforce appropriate behavior change, problem-solve obstacles to adherence	– Data should be gathered on the timing and duration of daytime naps – Gathering additional data on the timing of daytime activities can be used to develop a structure for daytime naps and activities

members of the patient's household are well-informed about the patient's condition and potential limitations. Specific areas to explore and provide education include: (1) prevalence, etiology, and symptoms of CH; (2) current treatment options; and (3) resources for further educational opportunities.

Ideally, the educational component is delivered early during the course of treatment. Clinicians who are not familiar with CH can review the section above (see Section "A primer of chronic hypersomnia") for reference. As part of the educational component, the clinician can also ask the patient to describe their journey to getting diagnosed with CH, since it takes most patients several years to get diagnosed and they are often referred to several providers before seeing a sleep specialist. This can provide an important first step in understanding the patient's perspective, establish rapport, and correct any misconceptions about their condition. Furthermore, being well-informed about their condition can empower patients to educate others (e.g., friends, co-workers, and acquaintances) about CH, which can improve interpersonal functioning, one of the main complaints of people with CH.

Regulating nighttime sleep

CH is not typically associated with severe symptoms of insomnia but people with narcolepsy can experience frequent awakenings and difficulty staying asleep. In addition, the sleepiness associated with CH can lead to irregular bedtimes and wake-up times, which can potentially exacerbate daytime sleepiness (Manber, Bootzin, Acebo, & Carskadon, 1996). Therefore, regulation of nighttime sleep is an important behavioral strategy that adopts elements from Sleep Restriction Therapy and Sleep Hygiene that are used in CBT-I. Instead of reducing time in bed as is typically done in CBT-I, the focus in hypersomnia is to set aside a regular "sleep window" that is established by having a regular bedtime and rise time. The rationale for not reducing time in bed is to avoid the exacerbation of daytime sleepiness that can occur as part of Sleep Restriction Therapy. Similar to sleep restriction, the sleep window can be set based on the average sleep duration obtained through sleep/wake diaries and collaborative discussion with the patient regarding factors such as chronotype, lifestyle preferences, and other responsibilities (e.g., occupational, child care). It is also important to discuss ways to protect the sleep window by encouraging patients to set reminder alarms for bedtime (e.g., "30-min warning") and alarms for the rise time. Patients should also be reminded that the sleep window should be followed on the weekends or off days in addition to weekdays or workdays.

Although sleep hygiene is typically associated with insomnia, clinical observations suggest that sleep hygiene is often inadequate in people with hypersomnia. Consequently, the removal or minimization of electronic devices and other items that might interfere with sleep during the sleep window should be emphasized. Similarly, an assessment of the sleep environment should be conducted and avoidance of activities such as work or watching TV in bed should be discussed as needed.

Clinicians should be aware that sodium oxybate is taken in two doses—one at bedtime and the second dose 2.5 to 4 h later. Since this second dose typically requires patients to wake up in the middle of the night, some patients can have difficulty falling back to sleep. In these situations, discussing stimulus control techniques, such as not attempting to go back to sleep until sleepy, could be useful to minimize the nocturnal sleep disturbance over time.

Regulation of daytime naps and activities

Regulation of daytime naps and activities is an important component for managing energy and alertness during the day. Although most people with CH will report taking naps, it is often ad hoc and used when they are at the point of exhaustion. Instead, developing a consistent schedule for prophylactic naps and activities that require high cognitive or physical resources can be a more efficient and effective way to manage energy throughout the day. Similar to the concept of a sleep window at night, this approach allows clinicians and patients to develop scheduled "nap windows" during the day and other windows for work, school, or leisurely activities.

Rather than approaching the day as one continuous period of wakefulness, patients with hypersomnia are encouraged to break up their waking hours from rising time to bedtime in smaller segments. For example, there can be a morning segment that is designated as a window for work, followed by a brief nap window (e.g., 20–30 min). For some patients with IH who might not be able to take short naps, a window of rest or relaxation can be substituted for the nap window. An afternoon window for work or physical activity can also be scheduled, followed by a second nap window (if appropriate) or a window for leisure activities. Finally, a window for evening activities can be scheduled, which could consist of social or leisure activities, leading to the nighttime sleep window. This approach is based on a time management strategy designed to split up larger intervals of time into smaller, more manageable components. This technique is used to improve focus and attention, and frequent breaks can improve cognitive functioning.

Unfortunately, the current evidence base has not revealed consistent evidence to provide guidelines on the optimal length or timing of naps. In addition, people with IH might have difficulty limiting naps to short periods. Therefore, clinicians should customize the daytime schedule to each CH patient based upon their symptoms, daytime responsibilities, and other schedule requirements. Having patients keep "daytime diaries" for activities and naps can be very helpful in developing the schedule and monitoring progress with adherence to the sleep schedule. Also, setting alarms or reminders can help to facilitate the transition from one window to the next. Some patients will be resistant to the idea of a daytime schedule, perceiving it to be constraining. In these cases, clinicians can explain that the purpose is not to be rigid, where one adheres regardless of circumstances, but to be consistent, which allows for some flexibility when needed with a return to the regular schedule when circumstances permit. In contrast to insomnia, people with hypersomnia generally do not have difficulty falling asleep during naps. However, in case this happens, clinicians should be prepared to adjust the nap timing by working with the patient to identify other times when they might be more sleepy and therefore more likely to nap.

Self-efficacy and self-esteem

In addition to the behavioral components, cognitive strategies directed at improving psychosocial functioning are essential, given the high rates of depression and anxiety in people with CH. For people with narcolepsy, there are issues related to self-image, self-esteem, and self-efficacy, which results from the stigma of narcolepsy, the constancy of low energy and sleepiness that adversely affects functioning, and the unpredictability of symptoms such as cataplexy (Ong, Dawson, Mundt, & Moore, 2020; Ong, Fox, et al., 2020). Although research is still in the nascent stages, preliminary work and clinical anecdotes have revealed a few promising techniques.

First, clinicians can assess the patient's understanding of their diagnosis and, if appropriate, help patients process their self-image as a person with CH. Those who have been recently diagnosed might not have accepted their diagnosis or processed their self-perception or how others see them. For example, some patients still have expectations to function at their premorbid condition. The clinician can discuss what it means to the patient to be diagnosed with hypersomnia and whether or not this has changed their career or family goals. This could lead to cognitive restructuring of the patient's expectations to more realistic levels that are commensurate with their symptoms and current level of functioning. If appropriate, clinicians can review the patient's stated values and help

patients establish new goals. This can improve both self-esteem and self-efficacy as patients are no longer judging their performance based on unrealistic expectations.

Addressing interpersonal issues can be very beneficial for patients who are encountering negative interpersonal interactions due to CH. In our pilot study (Ong, Dawson, et al., 2020), therapists engaged in discussions about the patient's experience in disclosing their CH diagnosis and any stigma that was associated with their experience. Clinicians can provide guidance about assertive communication, a style of communication that expresses both positive and negative feelings in an open, honest, and direct way, versus aggressive communication, a demanding or authoritarian style of communication that involves personal attacks and threats. In addition, it can be helpful to discuss social support. Clinicians should assess the support structure in the patient's current home or work environment and discuss ways to increase support. If there are issues related to managing hypersomnia symptoms at work or school, a discussion about disability accommodations and how to approach employers or teachers could be appropriate. Given that CH is a rare condition, many patients might not have met another person with CH. Providing resources for patients to connect with organizations that support people with narcolepsy (Wake up Narcolepsy, Narcolepsy Network) and Idiopathic Hypersomnia (Hypersomnia Foundation) can enhance psychosocial support.

Mindfulness and acceptance

Mindfulness and acceptance-based techniques can also be used for managing the emotional burden associated with CH symptoms. Patients may not be able to fully engage in social settings at times due to feelings of sleepiness or may choose not to socialize altogether. Discussion of the principles of self-compassion can be very helpful since patients often feel guilty or disappointed about their level of functioning.

Since there is currently no cure for narcolepsy or IH, the concept of active acceptance can be useful to manage frustrations and disappointments related to the constant feeling of sleepiness and fatigue or the unpredictability of certain symptoms such as cataplexy. In active acceptance, the individual makes an *active* decision to accept or embrace the situation even if the outcome cannot be changed. In the case of CH, it is to acknowledge or embrace the fact that one has a diagnosis of CH and that it cannot be changed, yet still choose to make decisions that are value-congruent. By practicing active acceptance, one is not denying that hypersomnia has limitations but rather working within those limitations to still engage in meaningful activities. For example, a person with CH might have had career ambitions of being a surgeon, but due to CH symptoms

did not have the stamina to complete surgical training. Instead, they *choose* to re-direct their interest in medicine by becoming involved in teaching medical students and residents and doing administrative roles in a medical clinic. This is in contrast to passive acceptance, which involves giving up, or the resignation that one has no control over the problem. By practicing active acceptance, it provides a way to work with the unpredictability of hypersomnia symptoms without always trying to control them, which can sometimes exacerbate feelings of depression and anxiety.

Helping patients identify personal values can help to establish priorities and maintain goals consistent with their personal values. The challenges of managing CH symptoms can results in significant functional limitations, making it difficult to maintain career or family ambitions. Clinicians can help patients identify core values by developing a values inventory, or list of values using the following questions:

- What is important to you?
- What gives your life meaning?
- At the end of the day, what really matters to you?
- What are the priorities and principles that guide your life?

Patients are then encouraged to set a goal or each of the values in their inventory. The focus should be on how they can achieve their specific goals in their current life or situation. Although some modifications might be needed, the key point is to help patients establish the possibility of living a life with activities that are consistent with their core values.

Conclusions and future directions

Behavioral Sleep Medicine is expanding in areas beyond insomnia and cognitive-behavioral strategies can play an important role in improving the HRQoL in people with CH. Building upon previous work using scheduled naps and regulating nighttime sleep, additional behavioral components of scheduled daytime activities can be used to reinforce structure for managing EDS. In addition, cognitive strategies designed to improve self-esteem and self-efficacy related to the unique psychosocial aspects of hypersomnia can provide important tools for CH patients to accept their diagnosis, cope with their symptoms, and address interpersonal issues related to living with hypersomnia.

The approach described in this chapter should be considered a starting point and future directions should be aimed at testing these approaches and other cognitive and behavioral strategies. Although preliminary findings support the feasibility of delivering these strategies into a CBT-H program (Ong, Dawson, et al., 2020) further research is needed to evaluate the efficacy of the program, individual components, or optimal combination

of components through randomized controlled trials. Research is also needed to examine the appropriate method of delivery for these strategies. A pilot study revealed that this CBT program can be delivered individually or in groups, although the group approach had somewhat more favorable outcomes (Ong, Dawson, et al., 2020) and has the benefit of peer support. Given that narcolepsy and IH are considered rare conditions, scalable delivery methods such as telehealth or digital programs (i.e., apps) can be particularly important to enhance the accessibility of these treatments for patients with CH due to their location or if their symptoms preclude traveling long distances. Additionally, components such as adherence to CH medications or family support groups could be considered or developed as separate intervention programs. Management of diet can be very important given the connections between orexin and diet regulation and could be examined as a possible module in CBT-H. Finally, research is needed to determine if this program is appropriate for patients with narcolepsy and IH or if separate programs with different approaches are needed. Moving forward, there is a clear need for more nonpharmacological interventions for hypersomnia to accompany the pharmacological treatments so that patients with hypersomnia can manage their symptoms effectively and achieve a high HRQoL.

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