

## Sleep Stewardship

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## AMA Journal of Ethics®

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### FROM THE EDITOR

#### Sleep Stewardship

Thomas Gossard, MD

In 1943, Abraham Maslow proposed his Hierarchy of Needs,<sup>1</sup> a pyramidal depiction of how our lower-level needs (eg, physiological requirements for food, clean water, clean air, shelter, hygiene, and sleep) must be met before we can pursue or promote our higher-level interests. Many of us take our basic requirements for granted, but one requirement will get clinical, ethical, and population-level attention in this issue of the *AMA Journal of Ethics*: sleep. Of course, everyone with a sleep disorder deserves equitable, timely clinical attention and intervention. This issue's focus is broader than sleep pathologies, however, and looks to investigate how sleep is perhaps best conceived as a communal natural resource, a basic physiological need.

The idea of sleep as a natural resource—because we must all be stewards of the conditions of sleep for one another—that deserves individual and **communal protection** has gained traction in the scientific and public health literatures. For disadvantaged populations, access to darkness, quiet, and even calmness can be limited due to structural, socioeconomic, and psychological factors. An extreme example is homeless shelters. While shelters and warming houses can provide a reprieve from the outdoors, there is often a lack of resources to provide the quiet and darkness necessary for restful sleep. This theme issue focuses on populations that can be disproportionately affected by inadequate communal sleep resources and how we can begin to address these social determinants of health as health care professionals.

In particular, this issue of the *AMA Journal of Ethics* examines key structural factors that underlie our modern sleep disturbances. A biological framework of sleep, for example, includes circadian rhythms that play an important part in adequate sleep hygiene. When one's rhythms are interrupted with artificial light, demanding work schedules, and social expectations, one's internal clock shifts. Increasingly, this pathological shift has been shown to play roles in physical and mental health. In fact, inequalities exist that have shaped entire groups' rhythms. This theme issue will discuss ethical questions about circadian rhythm maintenance. One factor that affects circadian rhythms, **artificial light**, will be discussed in greater detail by a physician member of DarkSky International.<sup>2</sup>

Some populations are at higher risk for more severe health outcomes from sleep disturbances. In the light of current events, one article in our theme issue will examine sleep in detained immigrant children and adults. It focuses on ambiguous policies surrounding torture, especially in the context of **sleep deprivation**. This theme issue will

also provide a framework for effectively addressing poor sleep quality of children of all backgrounds in time-limited clinic visits, with attention to contributing social and environmental factors.

Finally, how do we address these issues in health professions education? The amount of sleep a medical student receives,<sup>3</sup> for example, does not align what that student is now formally taught about sleep's importance to health. A pathway to better sleep care for patients begins with education, and an article in this issue will discuss the prior and next steps that must be taken to properly educate health professionals about the importance of sleep and how to treat patients with sleep trouble. With that knowledge, this theme issue will also discuss how to care for **patients with sleep trouble** in practice, along with some currently available therapeutic options. Finally, a trio of experts with extensive backgrounds in socioeconomic factors affecting sleep health discuss public health policies relevant to sleep duration and sleep quality.

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**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**Who Should Talk to Patients and How About Whether They Have Access to Sufficient, Quality Sleep?**

Maeve Pascoe, MD, MS and Nancy Foldvary-Schaefer, DO, MS

**Abstract**

Primary care clinicians are well-equipped to screen for sleep concerns, help some patients, and refer patients whose sleep troubles are more complex to specialists. Poor sleep affects nearly every organ system and influences many morbidity and mortality causes, so screening for sleep sufficiency and quality should be prioritized in primary care settings. This commentary on a case suggests strategies for more fully supporting primary care clinicians' compensation and capacity for conducting effective conversations with patients experiencing sleep trouble.

**Case**

Dr T is a faculty member in a large academic health center who regularly lectures on home safety, diet, food access, smoking status, alcohol use, exercise patterns, and income sources as key determinants of patients' health status and access to good health outcomes. "If you're going to be a good clinician," Dr T suggests to students attending today's medicine grand rounds, "You must consider roles each of these factors play in the lives of each of your patients during the brief time you spend with them, especially in patients with chronic conditions."

"And don't forget that how long and how well your patients sleep is also critical. When I say 'critical,' I mean as important as food security and shelter. Finally, sleep is getting the clinical attention it deserves, so be prepared to integrate sleep queries into your history intake and physical examination practices."

Dr D sits among the audience members, gestures to speak, and then asks, "Sleep as important as food and shelter? We have to be careful not to just add to the list of things physicians have to ask their patients about."

Dr T responds, "I'm going by the data here, Dr D. Many of our patients are sleep deprived. Sleep is critical, and we need to be asking about it in primary care settings."

"Well, then, what is sleep medicine for?" Dr D queries. "We can't dump everything on primary care, and we can't make everything a public health emergency."

Members of the audience consider whether and how to integrate conversations about sleep into their encounters with patients.

### Commentary

Primary care physicians are the primary point of contact between patients and the health care system. Typically, patients will have the same primary care physician for many years, giving ample time for longitudinal, trusting relationships. During primary care visits, when physicians both inquire about specific disease states and conduct general screenings, holistic health is at the forefront of the conversation, and this conversation would be incomplete without a discussion on sleep.

Although sleep medicine is its own distinct field with specialized education and training, sleep touches on nearly every other field of medicine. Just as food and water are essential for providing energy and sustaining life, so quality sleep is essential for clearing away metabolites in the brain, as it allows for adequate memory consolidation during rest and mental concentration during waking hours and maintains vital functions like breathing.<sup>1,2,3</sup> Neurologically, poor sleep can worsen seizures in epilepsy; contribute to sudden, unexplained death in epilepsy cases; and contribute to the formation of neural amyloid plaques associated with Alzheimer's dementia.<sup>4,5</sup> Additionally, sleep may worsen chronic systemic diseases commonly treated by primary care physicians. According to the Centers for Disease Control and Prevention, some of the leading causes of death in the United States are heart disease, cancer, stroke (cerebrovascular diseases), chronic respiratory diseases, and diabetes.<sup>6</sup> Forty percent to 80% of patients with "hypertension, heart failure, coronary artery disease, pulmonary hypertension, atrial fibrillation, and stroke" have comorbid **obstructive sleep apnea** (OSA),<sup>7</sup> and the combination of OSA and chronic obstructive pulmonary disease worsens clinical outcomes.<sup>8</sup> Likewise, poor sleepers have a 1.45-fold higher hazard of cancer mortality than healthy sleepers, while sleep duration and sleep disorders may increase risk for development of lung and gastrointestinal cancers as well as obesity and type 2 diabetes.<sup>9,10,11,12</sup> Furthermore, poor sleep and stroke-related mortality have a dose-dependent relationship.<sup>11</sup> From these few statistics alone, the effects of poor sleep on general mortality should be clear, as well as the role of sleep assessment as part of the primary care physician's preventive health efforts.

### Implementing Sleep Assessments in Primary Care

Primary care is the ideal setting for initial sleep screening to take place, as preliminary assessments can help clinicians triage referrals to sleep medicine clinics. Initial evaluations could be informal discussions stemming from common patient concerns (eg, "I just can't seem to get through my day without several cups of coffee") or systematic components of the physician's routine social factors assessment. Additionally, researchers and clinicians are partnering to make sleep health screening as easy as possible by optimizing in-office screening,<sup>13</sup> as well as by creating smartphone applications for sleep-related questionnaire completion ahead of patient visits.<sup>14</sup> Current data indicate that electronic screening for common sleep conditions is feasible and leads to further treatment.<sup>15</sup> Sleep apps can also help patients track their sleep and become more educated about sleep hygiene, thereby reducing prevalence of poor sleep.<sup>16</sup> Finally, smart-wearable devices can collect sleep data interpretable by primary care clinicians with similar efficacy to actigraphy,<sup>17</sup> which can save time on screening.



As with many other issues, such as food insecurity or smoking, once clinicians identify sleep problems, they can ask further questions to address patients' access to resources or educational gaps. For example, discussing a patient's nighttime phone usage could lead to an assessment of the patient's willingness to change or improve their sleep hygiene (using techniques currently implemented for smoking and substance cessation) and to provision of sleep hygiene information (similar to patient-centered education materials about medication administration or dietary changes). In other cases, discussions may provoke concern about specific sleep disorders. Initial testing for disorders like sleep apnea may be done with home sleep apnea testing, and primary care clinicians can initiate continuous positive airway pressure (CPAP) therapy for individuals who qualify. However, patients who cannot achieve adherence to CPAP therapy or for whom other disorders are suspected can be referred to sleep medicine by their primary care clinicians. At sleep medicine clinics, physicians can conduct further workup—including multiple sleep latency tests, maintenance of wakefulness tests, and polysomnography—and implement additional therapies, such as **cognitive behavioral therapy for insomnia** or hypoglossal nerve stimulation for sleep apnea.<sup>18,19</sup>

### **Protecting Time for Sleep Screening**

In addition to recognizing the importance of sleep screening and referrals to sleep medicine from primary care, it is equally important to recognize the primary care physician's time as a precious resource. Primary care physicians increasingly have more work with far less time per visit. The average primary care appointment lasts only 18 minutes,<sup>20</sup> while more than half of US adults have 3 or more chronic conditions,<sup>21</sup> on top of concerns about home safety, diet or food access, smoking status, alcohol use, and exercise patterns—all of which are vital to patient health outcomes<sup>22</sup>—that must be managed during that appointment. In order for health systems to give primary care physicians more time for these important conversations, physicians must be able to be reimbursed.

Currently, US Preventive Services Task Force (USPSTF) screening recommendations with grade A or B evidence (ie, “high or moderate net benefit for patients”) are covered completely by Medicaid reimbursement, while those services not listed as USPSTF A or B have no such guarantee.<sup>23,24</sup> Just as there are USPSTF A and B recommendations for screening for healthy diet, physical activity, and tobacco and alcohol use, so identifying appropriate USPSTF A and B recommendations for sleep screening would greatly aid reimbursement for this vital activity and thereby ensure that the primary care physician's time spent on this issue is valued. While streamlined screening and use of technology to collect and evaluate sleep data would help physicians save time, USPSTF guidelines would provide justification and compensation for the time taken for sleep screening.

### **Conclusion**

While sleep screening may not initially seem vital in the primary care setting, neglecting an aspect of health that affects every organ system and most major pathologies actively prevents patients from achieving holistic health. The best hypertensive medications will have little effect without airway patency during sleep, and neurorestoration after stroke cannot occur without adequate nighttime rest. Addressing the **root cause of health issues** gives clinicians the best chance at providing holistic health care for patients, and one of the root causes of disease for many patients is poor sleep. It is necessary for primary care physicians to perform preliminary sleep screening to triage care, and, for that to happen, it is necessary for the health care system to value sleep enough to fully

support primary care physicians with time, screening resources, and funds as they perform this important work.

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**Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should Clinicians Partner With Families to Promote Children's Sleep Health?**

Ariel A. Williamson, PhD, DBSM

**Abstract**

Short sleep duration, poor sleep quality, and irregular timing of sleep are prevalent sleep troubles for children, but fully assessing children's sleep environments and effectively promoting children's overall sleep health is nearly impossible during brief clinical encounters. This commentary on a case suggests strategies for navigating this problem with a patient- and family-centered approach that prioritizes identifying family sleep-related beliefs, values, and goals and maintaining flexibility when offering evidence-based recommendations to improve children's sleep.

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**Case**

LJ is a 12-year-old arriving with their parents to an appointment with Dr Z. LJ has been more distracted and disruptive in school, their grades have dropped from a B+ average to a C, and a teacher recently mentioned seeing them dozing during class. Dr Z speaks with LJ alone and learns that LJ's father was recently laid off from a long-time job, prompting the family to sell their home and move to an apartment. LJ's mother has taken on 2 new jobs and is often not home until 11:00 pm, past LJ's bedtime, which is now much harder for LJ's parents to enforce. LJ now plays video games late into the night, delaying sleep onset, and typically wakes up a few hours later due to noise from neighbors in an adjacent apartment or on the stairs. LJ's mother can no longer drop them off at school, so LJ must be prompt to catch the school bus at 7:00 am. Most nights, LJ gets 5 to 6 hours of sleep. LJ also tells Dr Z, "My mom and dad aren't very happy right now. I make things worse for them when I don't do well in school." LJ and their family have identified LJ's daytime sleepiness and poor grades as top problems at this visit. Dr Z considers how to address these changes in LJ's life and LJ's shortened sleep duration with their parents.

Dr Z wonders how to recruit LJ's parents as allies in protecting LJ's sleep time and quality.

## Commentary

Child sleep health is multidimensional and determined by multiple factors. LJ's case reflects how many social and environmental factors, including family transitions and related stress, caregiver work schedules, the home sleep environment, school start times, and the **neighborhood context**, can interact to produce poor pediatric sleep health.<sup>1,2</sup> Importantly, pediatric sleep health comprises multiple domains that are represented by the Peds-B-SATED framework: pediatric sleep-related behaviors (eg, nighttime electronics usage), satisfaction (perceived sleep quality), alertness during the day, timing of sleep, efficiency of sleep (ie, continuity or awakenings), and sleep duration.<sup>2</sup>

LJ's concerns cut across nearly all sleep health domains. LJ's evening video gaming is a poor sleep health behavior that has led to a later bedtime and a prolonged sleep onset latency, as electronics usage before bedtime can increase stimulation and disrupt sleep.<sup>3,4</sup> To assess satisfaction with and timing of sleep, Dr Z could ask LJ about their perceived sleep quality and sleep schedule during weekdays and on weekends, respectively.<sup>2</sup> Night awakenings due to neighborhood noise reflect poor efficiency or continuity of sleep, likely contributing to daytime sleepiness (ie, diminished alertness).<sup>2</sup> Further contributing to diminished alertness at school,<sup>5</sup> LJ experiences insufficient sleep duration, as 5- to 6 hours is less than the 9-to-12-hour total sleep duration recommended for children aged 6 to 12 years.<sup>6</sup>

Sleep and child well-being are closely linked.<sup>7</sup> There is robust evidence that short sleep duration in childhood is associated with worse academic performance, worse mental health, and increased risk of obesity and other cardiometabolic concerns.<sup>7</sup> Especially relevant to LJ, experimental research shows that sleep-restricted youth are more likely to experience inattention, irritability, and emotional lability.<sup>8,9</sup> Although less research is available on other aspects of sleep health, such as daytime sleepiness<sup>10</sup> and irregular sleep timing,<sup>11</sup> these aspects are similarly associated with adverse child outcomes, including mental health problems. Thus, poor sleep health likely contributes to LJ's current academic and psychosocial difficulties. There is also evidence that poor sleep health could exacerbate the impacts of lower family socioeconomic status and related stressors on child cognitive and mental health functioning,<sup>12,13,14</sup> making it even harder for LJ to cope with recent family changes. Given the link between poor child sleep and depressive symptoms and suicidality,<sup>15</sup> Dr Z should also consider administering available child mental health screeners (eg, the Patient Health Questionnaire-9 item depression screener<sup>16</sup>) to identify whether the family could benefit from a mental health referral.

### **Patient- and Family-Centered Care Is Needed to Promote Child Sleep Health**

Ethically protecting child sleep time, sleep quality, and sleep health more broadly requires a patient- and family-centered approach,<sup>17</sup> which is associated with increased patient and family care satisfaction and improved health care outcomes.<sup>18,19</sup> Key principles of this approach include **communication and collaboration** with patients and families in health care planning and decision-making, recognizing and drawing upon patient and family strengths, and promoting health literacy.<sup>18,19</sup> Simply providing LJ and their caregivers with sleep health recommendations, including age-based sleep duration guidance, prescribing an earlier bedtime, and removing video games, may feel impossible for the family, given the less modifiable factors contributing to LJ's poor sleep (see Table). For instance, it is unlikely that LJ's mother can change her work schedule. Moreover, removing electronics may be difficult if LJ uses video games to

cope with family and school stress, distract from pre-sleep worry, or tune out neighborhood noise.<sup>20</sup> Yet LJ cannot wake later in the morning to extend sleep duration since the family must rely on an early school bus for LJ's transportation. LJ also may attend a middle school that starts earlier than the later times that better align with emerging preteen and adolescent social and circadian rhythms.<sup>5,21</sup>

**Table.** Child Sleep Health Domains, Guidance, Barriers, and Potential Adaptations

Peds-B-SATED domains <sup>a</sup>	EB sleep health guidance ("hygiene") <sup>b</sup>	Social and environmental barriers	Family-centered care adaptations <sup>c</sup>
<ul style="list-style-type: none"> <li>• <i>Behaviors.</i> Activities that support or undermine sleep</li> <li>• <i>Satisfaction (quality).</i> Subjective assessment of sleep as good, poor</li> <li>• <i>Alertness.</i> Extent of daytime wakefulness (ability to stay awake)</li> <li>• <i>Timing.</i> Sleep placement in 24-hour day</li> <li>• <i>Efficiency (continuity).</i> Ability to easily fall asleep and return to sleep after awakenings</li> <li>• <i>Duration.</i> Total 24-hour sleep duration</li> </ul>	<ul style="list-style-type: none"> <li>• Follow consistent wind-down/bedtime routine</li> <li>• Turn off electronics 30-60 minutes before lights out</li> <li>• Avoid caffeinated beverages</li> <li>• Keep bedroom quiet, dark, and cool</li> <li>• Maintain consistent sleep schedule</li> <li>• Obtain 9-12 hours of sleep per 24 hours (for children aged 6-12 years)</li> </ul>	<ul style="list-style-type: none"> <li>• Limited night supervision and caregiver-regulated sleep schedule due to caregiver work demands</li> <li>• Increased independence and access to electronics</li> <li>• Overcrowded, noisy homes and neighborhoods</li> <li>• School transportation needs</li> <li>• Early school start times</li> <li>• Normative delay in circadian timing during adolescence</li> <li>• Child and family stress</li> </ul>	<ul style="list-style-type: none"> <li>• Assess family beliefs about patient's top problems, sleep concerns, and sleep needs.</li> <li>• Prioritize family-identified goals and culture and shared decision-making</li> <li>• Avoid prescribing sleep duration and bedtime in favor of collaborating with family to identify how to extend sleep duration on school nights</li> <li>• Consider temporarily later bedtime as family makes sleep changes</li> <li>• Develop family media plan using a harm reduction approach to minimize electronics exposure before bedtime while maximizing feasibility and sustainability of change for family</li> <li>• Incorporate video- or cell phone-based check-ins so caregiver working evenings can remind child of bedtime</li> <li>• Integrate wind-down/bedtime routine with patient- and family-generated activities</li> <li>• Consider overnight use of ear plugs for noise if safe and acceptable</li> </ul>

Abbreviation: EB, evidence-based.  
<sup>a</sup> Meltzer et al.<sup>2</sup>  
<sup>b</sup> Paruthi et al,<sup>6</sup> Allen et al,<sup>22</sup> Meltzer and Crabtree.<sup>23</sup>  
<sup>c</sup> Bauducco et al,<sup>3</sup> Hartstein et al,<sup>4</sup> Williamson et al,<sup>24</sup> Dong et al.<sup>25</sup>

To apply a patient- and family-centered approach, Dr Z should collaborate with LJ and their family to tailor evidence-based sleep recommendations<sup>22,23</sup> to the family context, relevant social and environmental factors,<sup>24</sup> and the family's perspectives on LJ's sleep.<sup>18,19</sup> Ethically, minor patients like LJ should be involved in pediatric health care decision-making, with the physician taking a supportive role to encourage patient and family discussion while also respecting patient confidentiality.<sup>26</sup> To promote health literacy as part of a patient- and family-centered approach, Dr Z could begin by providing psychoeducation about how poor sleep health may contribute to LJ's current challenges using specific examples from the family's report of LJ's home and school functioning. Dr

Z should emphasize the link between sleep and overall well-being and clearly communicate that improving sleep may benefit LJ's functioning and help them cope with recent family stressors.<sup>27</sup> In this discussion, normalizing the high rates of poor sleep health in children may facilitate a nonjudgmental interaction and help Dr Z join with LJ's caregivers to promote healthier sleep. For example, Dr Z could share that more than 50% of middle school students do not obtain sufficient sleep on school nights<sup>28</sup> and that many have trouble setting technology aside at bedtime.<sup>20</sup>

Positioning LJ and their parents as the experts on LJ's sleep is crucial in joining with the family as an ally and generating feasible patient- and family-centered sleep health promotion strategies.<sup>24</sup> Accordingly, Dr Z should directly ask LJ and LJ's family about their sleep-related beliefs, goals, and any perceived barriers to healthy sleep.<sup>24</sup> It could be that LJ believes engaging in video games helps distract them enough to fall asleep<sup>20</sup> or that LJ or their parents do not feel LJ needs as much sleep as is recommended by national guidelines. Understanding these perspectives, along with family-identified goals and perceived barriers, can support subsequent collaboration<sup>18,19</sup> in addressing LJ's sleep. As shown in the Table, evidence-based sleep health guidance could be tailored to better align with the family context. Instead of prescribing a specific bedtime and sleep duration for LJ, Dr Z could work with the family to identify a bedtime—not too early in the evening—that would enable LJ to get the most sleep possible. Getting into bed too early could exacerbate LJ's reported difficulty falling asleep, and it may be necessary to begin with a temporarily later bedtime (eg, 11:00 pm) that is gradually moved earlier as the family makes other sleep changes.<sup>23</sup> Although LJ may be prepubertal, it could also be helpful to make the family aware that adolescents normatively experience a circadian delay with the onset of puberty, with a preference for later bedtime due to both biological and social factors (eg, increased independence, more social activities).<sup>21</sup>

To begin partnering with the family to address LJ's sleep, Dr Z should collaborate with the family members to develop brief, tailored wind-down or bedtime routines that include reducing electronic device use and encouraging activities that reduce hyperarousal before bedtime.<sup>23,25</sup> Dr Z should emphasize the importance of caregiver involvement in establishing bedtime routines and limiting screen time,<sup>3,29</sup> while also acknowledging any identified family sleep-related beliefs, goals, and barriers. Rather than recommending that LJ avoid electronics altogether 30 to 60 minutes before bedtime,<sup>4</sup> which may not be realistic for many youth, Dr Z could engage the family in collaborative problem-solving to set a patient- and family-identified video game and electronics stop time as part of a family media plan.<sup>29,30</sup> The family and LJ could also set reminders on their cellular phones to turn the game off, initiate video check-ins before bedtime if the caregiver who is working can take a break,<sup>24</sup> or enable parental controls to block internet access after a certain time each evening. Similar to patient- and family-centered care, collaboration and promotion of autonomy are core motivational interviewing principles.<sup>31,32</sup> By using motivational interviewing approaches,<sup>25,31</sup> such as exploring the advantages and disadvantages of reducing video game usage at night, Dr Z could help engage LJ in problem-solving and help facilitate positive change.<sup>32</sup> Rather than eliminating evening electronics usage altogether, Dr Z and the family could develop a harm reduction approach consisting of incremental, sustainable reductions<sup>33</sup> in video game usage. LJ could also earn video game time the next day if he is able to adhere to the family-identified school night bedtime.

Dr Z should also suggest that the wind-down or bedtime routine incorporate strategies for helping LJ cope with any low mood or negative self-referential thoughts concerning



sleep, school performance, and family stress.<sup>25,27</sup> Such strategies might include relaxation techniques and the development of coping thoughts (eg, *I am working on my sleep to do better at school or this is a stressful time for my family, but it will get better*) to replace negative thoughts reported by LJ during the visit. Throughout this discussion, Dr Z should continue to collaborate with both LJ and their caregivers to personalize these recommendations and address barriers to implementation.<sup>33</sup> Finally, if it is acceptable to the family and safe for LJ, ear plugs could be used overnight to block out neighborhood noise. Using a sound machine or white noise cellular phone app, with the phone plugged in across the room or set face down to prevent usage, could also help to reduce sleep-interfering noises overnight. Collaborating with the family to finalize an agreed-upon sleep plan using importance and confidence rulers—another motivational interviewing strategy<sup>31,32</sup>—could help Dr Z assess each family member’s perceptions and facilitate behavior change.<sup>33</sup>

### Conclusion

Developing a tailored plan to address poor pediatric sleep health can be challenging during a time-limited well-child or follow-up visit. Providing written **sleep health education** could increase clinical efficiency, but education is rarely sufficient for producing meaningful behavior change.<sup>34</sup> More specifically, applying a one-size-fits-all approach to sleep guidance neglects the crucial social and environmental factors underlying sleep health disparities, which begin in childhood.<sup>1</sup> Taking the time to position LJ and their family as experts and to engage them in generating personalized, feasible strategies to improve LJ’s sleep would likely yield greater patient and family benefits<sup>18,19</sup> and could motivate subsequent behavior change.<sup>33</sup> At the very least, a patient- and family-centered approach would help Dr Z join with the family as an ally and avoid contributing to the family’s already high level of social and environmental stress.

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

## When Should Pharmacological Interventions for Insomnia Be Recommended?

Brandon Peters, MD and Maxwell Sarver, MD

### Abstract

This commentary on a case describes how social determinants of health also contribute to insomnia and then suggests how to balance risks and benefits of different strategies for managing chronic insomnia. Behaviorally induced insufficient sleep syndrome can exacerbate morning side effects of prescription sleep aids, and there are potentially serious long-term risks (eg, dementia, falls, death) associated with chronic benzodiazepine use. Before trying sleeping pills, chronic insomnia should be treated with cognitive behavioral therapy.

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### Case

Dr D sees CC, a 46-year-old patient who struggles to sleep well. CC is a parent and works between 55 and 60 hours per week at 2 jobs. CC's family lives where there is frequently noise outside of their home at night. CC has trouble falling asleep and trouble staying asleep, with sleep interrupted by periods of wakeful anxiety. In total, CC probably logs about 5 hours of sleep per night.

Over the years, CC has tried over-the-counter melatonin, a dietary supplement, and diphenhydramine (an antihistamine). CC is currently on eszopiclone, a central nervous system depressant, which Dr D prescribed, but CC would like to change, since the eszopiclone makes them feel “hung over” in the morning. CC asks Dr D, “May I get a prescription for something else? You once prescribed benzos and they worked really well.”

Dr D considers whether a benzodiazepine (eg, alprazolam, clonazepam, or diazepam) would be appropriate. Dr D also wonders, “With these drugs, I’m treating the symptom of insomnia, when they work, but not the causes of CC’s long-term life stress, worry, and environment. Do the short- and long-term side effects of these drugs balance or outweigh the risks of untreated lack of sleep?”

Dr D considers how to respond to CC’s request.

## Commentary

When reviewing this scenario, it is easy to identify with a patient who, facing pressure from both professional and personal demands, discovers that their own sleep suffers. Sleep is a pillar of health and well-being, affecting nearly every aspect of optimal wakeful function. It is sacrificed or lost—to the detriment of an individual and the broader society—sometimes with serious adverse consequences. At what potential cost should opportunities for adequate sleep quantity and quality be protected, restored, or enhanced? Pharmacological interventions are frequently employed, but their use can be limited.<sup>1</sup> Honest accounting of how these medications work and their potential for both short- and long-term harms should, we argue, prompt wider use of important alternatives for managing chronic insomnia, including cognitive behavioral therapy for insomnia (CBTI). The rest of this commentary explores how to optimize the clinical assessment of insomnia, normative data and basic sleep concepts that contextualize patients' experiences of insomnia, and treatment strategies that promote best outcomes with the least risk to both the individual and society.

### Clinical Assessment of Insomnia

When clinically **assessing someone's sleep**, it is important to start by conducting an interview to understand the basics of their sleep routine.<sup>2</sup> This query should ascertain the typical bedtime, the average time it takes to initially fall asleep (ie, sleep-onset latency, or SOL), the average total time spent awake in the night after initially falling asleep and before the final awakening (ie, wakefulness after sleep onset, or WASO), and the typical time to get out of bed at the end of the sleep period (usually at morning awakening).<sup>3</sup> It is also useful to learn how bedtime and final wake time vary on days off from work, such as weekends, as significant variance may be present and contributes to a recurring **circadian misalignment** known as social jet lag.<sup>4</sup> A useful assessment framework is the SATED (satisfaction, alertness, timing, efficiency, and duration) questionnaire.<sup>5</sup> Symptoms and signs of other sleep disorders, including sleep apnea, restless legs syndrome, and delayed sleep phase syndrome, may also be relevant.<sup>2,6</sup>

In this example, a caregiver with multiple jobs may have a behavioral sleep restriction, leading to a discrepancy between the opportunity and ability to sleep. When prolonged wakefulness (self-reported SOL or WASO of more than 30 minutes) intrudes into this limited window for potential sleep, insomnia may contribute to further difficulties. Insomnia is caused by predisposing (ie, genetics), precipitating (eg, stressors, environment), and perpetuating (eg, poor sleep habits, altered relationship to sleep, untreated anxiety) factors.<sup>7</sup> Chronic insomnia is insomnia that occurs at least 3 nights per week and lasts for at least 3 months.<sup>8</sup> It may be associated with unrefreshing sleep, fatigue, decreased energy, headache, pain, malaise, dyspepsia, cognitive dysfunction, and mood complaints.<sup>9</sup> Insomnia is the most common sleep complaint encountered in the primary care setting, affecting 1 in 10 people.<sup>9</sup>

Normal sleep is enhanced by optimizing the factors that influence the homeostatic sleep drive and circadian rhythm, including a consistent sleep-wake schedule and obtaining 15 to 30 minutes of morning light exposure.<sup>10</sup> The average sleep need for adults is 7 to 9 hours, and those aged 65 years and older may need an average of 7 to 8 hours.<sup>11</sup> CC's only getting 5 hours of sleep per night, as reported in the case, indicates a significant compromise for a 46-year-old. This self-assessment can be supported with longer-term sleep logs kept by CC over several weeks or the integration of data from data collection devices worn by CC, although few studies have objectively assessed device performance among individuals with insomnia.<sup>12</sup>



### **Contextualizing Risks of Insomnia**

Beneficence is an ethical imperative to act in the patient's best interests<sup>1</sup>—in this case, to correct sleep deficiencies. Insomnia is a known risk factor for depression, anxiety, alcohol or drug use, suicide, chronic pain, and social and occupational dysfunction.<sup>13,14,15,16</sup> In addition, chronic sleep deprivation can have serious health consequences, affecting everything from metabolism to immune system and cardiovascular function.<sup>17,18,19</sup> Moreover, as the first author (B.P.) has written elsewhere, based on studies of cognitive performance<sup>20</sup>:

Studies have shown that sleep deprivation can profoundly affect memory and performance. Attention, concentration, and vigilance become impaired. People who sleep less than 7 hours per night have reaction times that are similar to those who are completely sleep deprived for one or even two nights. This leads to errors, accidents, and impaired work performance. The scary thing is that when you are chronically sleep deprived, you may not even recognize the level of impairment.<sup>21</sup>

Sleep loss thus leads to chronic, insidious problems that undermine health and quality of life as well as to immediate risks that threaten life itself. These effects may be due, at least in part, to disturbance of the glymphatic system, a perivascular network that flushes metabolites from the brain's tissues during sleep.<sup>22</sup>

Given these potential consequences, a medical professional might be quick to reach for the prescription pad to deliver relief. There is little guidance from the national medical academies (eg, the American Academy of Sleep Medicine, the American College of Physicians) with regard to when pharmacological interventions, especially benzodiazepine agents, are preferred due in part to a paucity of longitudinal efficacy and safety data.<sup>23,24</sup> In this scenario, the patient is currently on eszopiclone, a non-benzodiazepine hypnotic with a half-life of approximately 6 hours (closer to 9 hours in the elderly), and is having a “hangover” effect in the morning, likely due to behaviorally induced insufficient sleep, and so requests a benzodiazepine.<sup>25</sup> Contrary to the impulse to accede to this request, the ethical standard of nonmaleficence (*primum non nocere*, or “first, do no harm”) must give a clinician significant pause.<sup>1</sup>

### **Benzodiazepine Medications**

Historically, benzodiazepines were used in the management of both acute and chronic insomnia in adults. This routine use was the result of several studies that showed benefits of short courses of benzodiazepines; however, the study populations were primarily nonelderly adults, and long-term follow-up results were lacking.<sup>26</sup> A more recent, large-scale study in the United Kingdom evaluated the all-cause mortality associated with the use of hypnotics over a 7.6 year period and demonstrated a more than 3-fold greater hazard of mortality with any sleep aid exposure.<sup>27</sup> Among the studied sedatives, benzodiazepines notably had the highest prescription rates and the highest individual mortality rate; there was also a dose-dependent increase in mortality.<sup>27</sup> While this study could only demonstrate correlation and not causation, there are several known adverse effects of all classes of benzodiazepines. These include increased risk for car crashes, cognitive decline, and falls or fractures.<sup>26</sup> Long-acting benzodiazepines (eg, diazepam, clonazepam) are generally better tolerated but may cause the morning hangover effect with associated cognitive impairment,<sup>28</sup> while short-acting benzodiazepines (eg, temazepam) have less of a hangover effect but have a higher risk of fractures.<sup>29</sup>

Benzodiazepines have also been shown to have a risk of dependence with long-term use. Dependence can lead to several risky or maladaptive behaviors, including driving under the influence, use in addition to other sedatives, rebound insomnia or anxiety with discontinuation, or replacement with other substances after discontinuation by a physician.<sup>30</sup> Interestingly, although clinicians often encounter these issues in elderly patients, the 12-month prevalence of a diagnosed hypnotic or anxiolytic use disorder is only 0.04% in those age 65 years and older, which may indicate that benzodiazepine use is an underrecognized problem by primary care clinicians.<sup>31</sup>

In addition, the long-term use of benzodiazepine medications has been associated with cognitive decline and dementia.<sup>32</sup> While benzodiazepines are known to cause short-term cognitive defects, several studies have demonstrated that, even after discontinuation, several domains of cognitive function continue to be impaired in long-term users.<sup>33,34</sup> Because there is some debate as to whether insomnia or anxiety can be early presentations of dementia,<sup>35</sup> it is unclear if benzodiazepines are causing cognitive decline or if they are being used to treat these prodromal symptoms.

Overall, the risks of benzodiazepine use for treatment of insomnia have been viewed as outweighing the benefits in the majority of cases, causing them to be listed on Beer's Criteria with a strong recommendation against their use, particularly in the elderly with known cognitive deficits or in those at high risk of falls.<sup>36</sup> The American Academy of Sleep Medicine recommends against long-term use of hypnotic medications, including benzodiazepine receptor agonist medications like eszopiclone, except in very specific circumstances,<sup>23</sup> which this patient has not met. What is an ethical sleep caregiver to do?

### **Cognitive Behavioral Therapy**

Since 2016, the American College of Physicians has recommended that all adult patients with chronic insomnia receive CBTI as their initial treatment.<sup>24</sup> Despite this recommendation, the prevalence of medication use remains high, with an estimated 8.4% of adults in 2020 reporting the use of a sleep aid every day or most days in the prior month, according to the Centers for Disease Control and Prevention.<sup>37</sup> Awareness of and access to CBTI are both paramount to delivering the gold standard of medical care for treatment of chronic insomnia. CBTI is a structured 6-week program that reinforces changes in sleep habits while addressing sleep-disruptive thoughts, emotions, and social pressures.<sup>38</sup> It may be delivered one-on-one by a therapist, in a shared medical appointment workshop, through online or app-based programs, or via bibliotherapy.<sup>39</sup> Key elements of CBTI include sleep consolidation, stimulus control, cognitive restructuring, relaxation training, and sleep hygiene advice. Significant improvement occurs within weeks, and long-term skills are provided that yield ongoing benefits even years beyond the training.<sup>40</sup> CBTI has no side effects.

The ethical principle of justice should inform the administration of CBTI, as it unfortunately still represents a scarce health resource that is unevenly distributed. In 2016, it was estimated that there were 752 behavioral sleep medicine practitioners capable of delivering CBTI worldwide; 88% live within the United States; and more than half live in just 12 states.<sup>41</sup> There are many cities, regions, states, and countries with no sleep medicine practitioners. Technology must be leveraged to amplify limited CBTI expertise and address these unmet needs.<sup>42</sup>

For patients who are unable or unwilling to engage in CBTI, the benefits afforded by the use of medications may outweigh the risks of potential harms associated with insomnia and sleep deprivation. As necessary, clinicians should venture to engage in shared decision-making to determine when and what pharmacotherapy should be employed. In this case, the use of a short-acting benzodiazepine (eg, temazepam) may be preferable if CBTI is not possible. Regular follow-ups with reassessment of need via a risk-benefit discussion may help mitigate undesirable consequences.

Finally, a broader perspective on the presented scenario appeals to the social determinants of health.<sup>43</sup> How can society best support the factors conducive to the sleep of individuals to **optimize community well-being**? CC's socioeconomic situation, which necessitates their working multiple jobs, may indicate lack of livable wages, education, or employment opportunity. Social support networks, or the lack thereof, may add to the burden of caregiving and other inequalities. The noise of the neighborhood—and even the safety of the built environment—are additional influences on this individual's sleep.

### Conclusion

Sleep loss has extensive and serious consequences, with detrimental effects that extend from the individual to society at large. The ethical treatment of chronic insomnia requires universally extending access to CBTI and (when possible) avoiding the use of benzodiazepine medications and their inherent risks. Yet, in specific circumstances, pharmacotherapy may have a role. Moreover, we must advocate for social change that promotes healthy sleep by according it a central place in the lives of individuals and implementing public health policy to protect this most basic, undeniable, and ubiquitous good.

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### MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

#### Neuroscience at the Core of a Sound Sleep Health Curriculum

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##### Abstract

Neuroscience should be at the core of a sound sleep health curriculum, especially in early classroom-based medical education. This article canvasses ways in which sleep medicine has been rapidly transformed by tele-sleep tools and by research on neurobiological mechanisms underlying sleep disorders and on comorbidities associated with sleep disorders, including stroke, traumatic brain injury, and movement or neurocognitive disorders.

##### Evaluating Sleep Medicine Curricula

Within the collective human experience, the sleep-wake cycle is a powerful force dictating the rhythm of our lives. When sleep disruptions occur, the impacts are far-reaching and can contribute to a variety of health consequences, including increased risk of cardiovascular disease, metabolic dysregulation, and psychosocial stress.<sup>1</sup> Sleep difficulties are ubiquitous, with 14.5% of American adults in the 2020 National Health Interview Survey reporting trouble falling asleep on most or all nights within a given month.<sup>2</sup> The complexity of sleep's relationship to all aspects of a person's life has led to the development of the concept of "somnomics" as part of the precision medicine toolbox,<sup>3</sup> which also houses genomics, proteomics, and personomics.<sup>4</sup>

Considering that all clinicians and clinicians-in-training have an informal curricular understanding of sleep medicine through their own experiences with sleep deprivation, it is a shame that the field is yet untethered to and limited within the formal medical curriculum.

Sleep medicine is interdisciplinary, with residency program applicants from fields as diverse as neurology, psychiatry, pulmonology, internal medicine, family medicine, **pediatrics**, otolaryngology, and anesthesiology. While this multitude of perspectives is celebrated and aids in the plasticity of the sleep field, more discussion needs to occur regarding how national sleep education should be introduced, organized, and championed to ensure that all future clinicians have effective, evidence-based sleep practices. We suggest here that neuroscience should be at the core of a sound sleep health curriculum and that medical school is the prime stage to lay the introductory groundwork.

## Neurobiology of Sleep

Sleep medicine training and clinical practice have rapidly transformed over the past decades in tandem with the elucidation of neurobiological mechanisms influencing sleep. The identification of the first *Drosophila* clock gene period in the 1980s, along with the subsequent discovery of genes and proteins on the endogenous transcription-translation feedback loop, led to the characterization of the oscillatory 24-hour circadian rhythm primarily dictated by the suprachiasmatic nucleus.<sup>5</sup> A wealth of research has been conducted over the years to explore the pathophysiology behind a variety of sleep disorders. Much of the work elucidating the mechanism behind narcolepsy took place in the 1970s in the first US sleep clinic, established as a narcolepsy clinic at Stanford University in 1964.<sup>6</sup> Researchers have recently identified the degeneration of orexin-producing neurons in the lateral hypothalamus as contributing to dysregulated rapid eye movement (REM) sleep architecture, with frequent REM sleep transitions seen in patients with narcolepsy.<sup>7,8</sup> Research on **insomnia** has yielded mixed evidence in support of the theory that the dysregulation of endogenous wake-promoting/sleep-suppressing molecules leads to the overarching hyperarousal observed in this disorder.<sup>9</sup> The 2022 Accreditation Council for Graduate Medical Education (ACGME) guidelines require that sleep fellows demonstrate knowledge of neurologic mechanisms governing sleep and wakefulness, and ACGME-approved revisions for 2024 include the neurologic pathophysiology related to sleep disorders.<sup>10,11</sup>

## Sleep Disorders Among Neurology Patients

Within neurology clinical practice, many patients with stroke, traumatic brain injuries (TBI), movement disorders, and neurocognitive disorders have concurrent sleep disorders as an accompanying process or as a direct result of their disorders. A recent meta-analysis of 64 000 patients with a history of strokes or transient ischemic attacks (TIA) noted that there was a higher prevalence of sleep disordered breathing, obstructive sleep apnea (OSA), insomnia, periodic limb movement disorder, and restless legs syndrome in these patient populations compared to the general population.<sup>12</sup> In fact, due to sleep disorders' association with poor outcomes for patients with cerebrovascular disease and their potential contribution to recurrence of stroke or TIA, the American Heart Association and the American Stroke Association have released guidelines encouraging clinicians to consider sleep studies for patients who have had strokes in order to try to mitigate risk factors.<sup>13</sup> With sleep apnea seen in around half to three-quarters of patients with stroke or TIA,<sup>13</sup> being proactive with this workup can be very fruitful. A meta-analysis of sleep disturbances in patients with TBI found that 50% of the study population developed sleep disturbances, including insomnia, posttraumatic hypersomnia, nightmares, OSA, and narcolepsy.<sup>14</sup> Sleep disorders are thus rampant within neurology clinical practice.

## A Neuroscience Basis

Considering the neurobiological roots of sleep and sleep disorders, as well as the complicated relationship between neurological and sleep disorders, it is important to present sleep content to trainees through a neurological lens. OSA is hugely underdiagnosed and undertreated in the stroke patient population. While OSA already has a high prevalence in the general population, with estimates of 34% for men and 17% of women in the United States having OSA,<sup>15</sup> a recent meta-analysis estimated that the prevalence of OSA in patients with stroke and TIA is even higher—around 71%.<sup>16</sup> Nevertheless, a recent cross-sectional study found that only around 2.2% of stroke patients ultimately obtained polysomnography tests for OSA diagnosis.<sup>17</sup> Taking into consideration that an estimated 690 000 people suffer strokes every year,<sup>13</sup> OSA is

vastly underdiagnosed in a very vulnerable patient population. Given that sleep apnea is associated with higher risk of future cerebrovascular events, higher mortality, depressed mood, and worse functional status in patients with strokes and TIA,<sup>13</sup> it is critically important to encourage physician education on addressing and treating sleep disorders within this population. Moreover, some clinical trials have demonstrated that early continuous positive airway pressure device use following stroke leads to improved stroke outcomes, functional status, and National Institutes of Health stroke scores.<sup>18,19</sup>

While certain neurological disorders can cause the subsequent development of sleep disorders, there are situations in which sleep disorders can be a harbinger of neurological disorders to come. REM sleep behavior disorder (RBD) is strongly associated with the development of future neurodegenerative disorders, as roughly 80% of patients diagnosed with isolated RBD develop Parkinson's disease, Lewy body dementia, or multiple system atrophy within the following 10 years.<sup>20</sup> Being well-informed regarding these relationships can ensure careful monitoring within the RBD patient population. For patients with Alzheimer's disease, insomnia is very common and is associated with worsened clinical outcomes, increased caregiver burden, and increased health care utilization.<sup>21</sup> A potentially bidirectional relationship between disordered sleep and dementia has additionally been suggested,<sup>22</sup> with studies demonstrating that sleep fragmentation is associated with incidence of Alzheimer's disease and rate of cognitive decline.<sup>23</sup> Further research is necessary to elucidate the neurobiological bases of this sleep disorder and potential future treatments. With the overall direct health care costs of sleep disorders in the United States being close to \$94.9 billion annually, there is a great need for the thoughtful organization and promotion of a standardized sleep curriculum to ensure effective sleep practices.<sup>24</sup>

### **Neurologically Based Sleep Medicine Curriculum**

Housing a standardized sleep medicine curriculum within the medical school neurology clerkship can maximize the number of medical trainees exposed to effective sleep practices and allow them to benefit from early practice under the guidance of neurology educators. Currently, opportunities for sleep medicine exposure in medical schools are still limited. A 2011 survey of sleep medicine education in 12 countries found that the average amount of time spent on sleep education was around 2.5 hours, with 27% of responding medical schools reporting that their school did not provide sleep education and the mean and median time spent on sleep education in the United States and Canada being around 3 hours.<sup>25</sup> Comparatively, a 2020 cross-sectional survey of medical schools in the United Kingdom found that the average amount of time spent on undergraduate sleep education was 3.2 hours, with the median being 1.5 hours.<sup>26</sup> Although residency programs throughout the United States offer opportunities to study sleep medicine, with the highest percentages reported being 90.8% of neurology residency programs and 85.7% pulmonary and critical care programs, less than 10% of programs produce fellows over 5 years and even fewer students pursue funding for sleep-related research.<sup>27</sup> There is clearly a great need to promote sleep education within medical schools. Neurology educators have previously established national objectives for neurology clinical experiences that include sleep medicine education in the undergraduate medical curriculum,<sup>28,29</sup> and *Neurology* has published on the need for sleep medicine as a core competency within the neurology clerkship.<sup>30,31</sup>

By entrusting neuroscience courses and neurology clinical experiences (eg, clerkships) with implementing a standardized sleep curriculum, educators can ensure that medical students are exposed to good sleep medicine practices throughout the different phases

of their training and encourage increased sleep fellowship interest. Moving forward, it will be important to build flexibility into the curricular content to accommodate various medical school environments and **resource availability**. Potential venues for curriculum development include flipped classrooms during the preclinical curriculum and tele-sleep opportunities during the neurology clerkship.<sup>31</sup> A large meta-analysis of academic outcomes in flipped classrooms demonstrated better exam scores and course grades than lecture-based classrooms,<sup>32</sup> and other studies have shown improved student satisfaction with flipped classrooms.<sup>33</sup> Within the clinical years, tele-sleep opportunities can be incorporated to allow students to assess the sleep environment and speak with patients' family members who witness sleep pathology. Tele-sleep opportunities additionally allow students to engage with more patients with neurological disorders that hinder clinic visits. At the same time, these virtual opportunities can allay concerns of overburdening the current preclinical and clinical medical school schedules by allowing students to engage in clinical visits from home. Such virtual opportunities will decrease student transportation time and decrease stressors by creating a more relaxed setting, allowing students to access educational material in real time during the clinical experience without causing disruptions. There are also mobile apps, such as MySleep101, which enable nonspecialists to provide sleep information to patients and allow patients to develop questions at home to address in clinic in order to make counseling more efficient.<sup>34</sup> Virtual opportunities can also increase inclusion of a variety of student populations interested in medicine. For example, at Johns Hopkins University, there are tele-sleep shadowing opportunities available to premed students through participation in the PreDoc program.<sup>35</sup> More recently, opportunities to do tele-sleep clinical electives have also been extended to neurology residents in other medical programs who are interested in sleep medicine but do not have opportunities for exposure to this field at their schools.

## Conclusion

Neuroscience and sleep medicine are intricately interwoven, as evidenced by both the neurobiological mechanisms dictating sleep disorders and the high prevalence of sleep comorbidities within the neurology patient population. Encouraging neurology educators to step up to champion a nationwide sleep curriculum early in medical school will ensure that the good practices learned today will remain good practices employed tomorrow.

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**MEDICAL EDUCATION: PEER-REVIEWED ARTICLE**

**Applying a Health Equity Lens to Better Understand End-of-Life Prognostication**

Newsha Nikzad, MD, Joelle Robertson-Preidler, PhD, MA, and Faith E. Fletcher, PhD, MA

**Abstract**

Racial and ethnic inequity exists throughout the lifespan, including at the end of life (EOL). Although prognostication is inherently fraught with uncertainty, many underrepresented minorities get prognoses that are overly optimistic, which can exacerbate inequity by depriving patients of details needed to make informed decisions and plan for EOL care. This article applies a health equity lens to facilitate better ethical and clinical understandings of how to care for patients of color more equitably at the EOL.

**Prognostication at the End of Life**

“How much longer do I have?” is one of the most crucial and ethically challenging questions posed by patients. End-of-life (EOL) care has become an increasingly important topic in medical practice in light of population aging, growing diversity, and complexities presented by the COVID-19 pandemic. Prognostication fundamentally informs EOL care and is integral to the process of informed decision-making.<sup>1,2</sup> A prognostic message has tremendous medical and psychosocial value, as patients and their loved ones use this information to guide treatment pathways, advance care planning, and decisions on how to live a meaningful life at the EOL. It is also important to note that a disproportionate amount of resources and care are utilized at the EOL and that inaccurate predictions of prognoses can result in a significant financial burden for patients and their families.<sup>3</sup> Clinicians are responsible for **communicating to patients** both a prognosis and the possibility that their prognosis may be inaccurate. Effective prognostic messages can improve trust and patient satisfaction and alleviate uncertainties and anxieties at the EOL, with the ultimate goal of helping patients attain goal-concordant EOL care.<sup>4,5</sup> Although prognostication is inherently fraught with a degree of uncertainty, underrepresented minorities (URM) receive prognostic messages that are disproportionately overly optimistic, which has implications for equitable EOL decisions and care.<sup>6,7</sup> These inaccuracies in

prognostication are poorly understood and inadequately discussed by the health care and ethics communities.

### **Prognostic Inequity**

Inaccurate and overly optimistic prognoses that influence decisions to pursue intensive treatment at the EOL can cause harm by depriving patients of informed decision-making and EOL planning. A 2019 opinion piece in the *New York Times*, written by a critical care and palliative medicine clinician, explored the reality of African American patients receiving too little care during life and too much care during the end of life.<sup>8</sup> While there are many factors that might contribute to EOL inequities, the author referred to more intensive care at the EOL for URM as a “temporary salve,” an attempt to mitigate the guilt and fear a clinician feels as part of a racist, oppressive health care system that many patients distrust.<sup>8</sup>

Justice with regard to resource allocation cannot be achieved in the remaining hours, days, or months of life in the face of structurally imposed harm over a lifetime. Qualitative research shows that URM’s lifetime experience of structural racism and bias in health care settings may lead to their underuse of EOL care services because they cannot conceptualize nonaggressive EOL care and often fear that aggressive EOL therapies will be withheld because of their race.<sup>9</sup> Clinicians’ failure to understand the compounded and accumulated **structural inequities** that contribute to patients’ loss of confidence in the health care system and underuse of EOL care can create barriers to effective communication and accurate prognoses.<sup>10</sup> These complexities may in part explain why prognostic communication occurs less frequently among URM patients.<sup>6</sup> Other research shows that overly optimistic prognostic messages are associated with less and later hospice use by minority patients, which is not supported by their stated EOL care preferences,<sup>7</sup> suggesting that overly optimistic diagnoses may lead to misalignment of treatment with patients’ EOL preferences.<sup>7</sup> Life-prolonging measures may, in fact, undermine patient values and engender undue financial distress for patients and their families.<sup>11</sup>

There are other barriers to accurate prognostication. Physicians’ limited understanding of the social and structural drivers that influence patient outcomes could distort the context in which they formulate prognoses. Furthermore, prognostic evidence is informed by clinical trials with limited racial diversity, perpetuating prognostication inaccuracy and norms that fail to reflect the realities and experiences of diverse patient populations.<sup>1</sup> Such biased prediction modeling may be exacerbated in the future with increased use of artificial intelligence, which fundamentally relies on data that might not be representative.<sup>12</sup>

### **Rectifying Prognostic Inequity**

Despite the limited literature on racial and ethnic disparities in EOL prognostication, existing evidence of health care bias and medical mistrust can be used to inform prognostication strategies and future directions for the medical community.<sup>8,13</sup> For example, enhancing trust and trustworthiness in

health care settings by giving consideration to patients' realities throughout all life stages is critical to improving EOL care for URM.<sup>11</sup> In particular, the application of a life-course perspective—which posits that health outcomes are shaped by earlier exposures to physical, environmental, and psychosocial influences and that these cumulative exposures contribute to health disparities—can advance health equity.<sup>13</sup> Beyond building trust, justice requires advocacy at the systemic level for structurally appropriate health care policies, accessible patient education, and more equitable, evidence-based practices.<sup>14</sup> In addition to applying a life-course perspective, justice entails providing URM with information and adequate prognostic knowledge by engaging them in patient-centered goals-of-care conversations and participation in EOL decision-making.

*Systemic level.* At a systemic level, the medical community should consider factors influencing inequitable access to care. For example, Medicare and Medicaid are largely responsible for inequitable access to EOL care for low-income URM. Indigenous and Native American patients frequently do not have access to EOL care because many tribal health organizations are unable to meet Medicare and Medicaid criteria for hospice services.<sup>14</sup> The expansion of available EOL resources would combat structural discrimination against URM and, by extension, alleviate disparities that skew prognostication and overall health outcomes for patients. Policy makers and clinicians should also prioritize quality of EOL care to meet the complex needs of URM. Along with these changes, mitigating prognostication disparities requires an expansion of current **perceptions of EOL care** among clinicians and their professional communities.

Furthermore, better communication about comprehensive EOL care could also help patients make more informed EOL decisions that align more closely with their values and preferences. For example, integrating religion and spirituality into EOL care directly aligns with the practice recommendations of the National Hospice and Palliative Care Organization.<sup>15</sup> While data show that Black and Hispanic patients disproportionately receive care from for-profit hospices that provide poorer quality of care, spiritual support should ideally be provided by entities that are preferred by patients, such as faith-based partners from their respective communities rather than outside vendors.<sup>16</sup> Furthermore, **culturally responsible interventions** entail diversifying the audience to whom EOL care services appeal, which can be achieved by strengthening social support through a diversified, multilingual workforce that includes URM. This diversification of perspectives would allow for the optimization and individualization of EOL care. It would also enhance understanding of the intersectional complexities<sup>17</sup> that we argue influence prognoses in URM, thereby potentially increasing accurate prognostication.<sup>17</sup>

*Individual level.* To decrease bias and prognostic inaccuracies at the individual level, clinicians can utilize existing prognostication scoring tools to increase objectivity and potentially minimize disproportionate optimism.<sup>18</sup> Since these prognostic tools may contain their own biases and are calibrated to inpatient settings for patients with malignancies, developers and individual users should

modify these tools by incorporating social determinants of health into their algorithms, and predictions should be modulated by the human insight of the clinician.<sup>18,19</sup> Further research is also needed to investigate disparities in prognostication across various URM groups. For example, there is a paucity of data on Middle Eastern or transgender patients experiencing prognostication disparities at the EOL.<sup>20,21</sup> Studies should also focus on aspects of identity that might influence prognosis, such as non-heterosexual and non-cisgender identity, homelessness, and other socially marginalized identities that are associated with the poor delivery of health care and adverse health outcomes.

### Conclusion

At all stages of life, URM are confronted with health and health care inequities. The medical community is ethically obligated to recognize, investigate, and combat this stark injustice. Improving prognostication across populations is an integral part of addressing persistent health disparities and providing appropriate care to URM. Advances in advocacy, medical sciences, predictive tools, and workforce diversity are necessary to achieve health equity for URM within and beyond the realm of prognostic communication. Furthermore, while this discussion focuses on EOL prognostication, clinicians have an ethical and professional duty to provide respectful and equitable care throughout all stages of life. Indeed, if death is often considered a vessel for lessons on life and living, the life course proves to be an illuminating lesson on death, dying, and inequities at the EOL.

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### HEALTH LAW: PEER-REVIEWED ARTICLE

#### Sleep Is a Human Right, and Its Deprivation Is Torture

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##### Abstract

Sleep is integral to human health and well-being; it is recognized as a fundamental right by international bodies. Nevertheless, deliberate sleep deprivation is frequently employed as a form of torture, violating the right to health. Legal cases such as *LeMaire v Maass*, *Ireland v UK*, and *Huertas v Secretary Pennsylvania Dept of Corrections* illustrate the varying interpretations of sleep deprivation as torture or cruel and unusual punishment. Ambiguity in domestic and international legal definitions underscores the need for collaboration between health and legal professionals. Clinicians can offer expertise about physiological and psychological consequences of sleep deprivation, which informs what legally counts as torture. This commentary explores the intersection of sleep deprivation, human rights, and the role of medical professionals in addressing, identifying, and preventing sleep deprivation as a means of coercion and abuse.

##### Case Law on Sleep

Samuel LeMaire was imprisoned in the Disciplinary Segregation Unit (DSU) in the Oregon State Penitentiary.<sup>1</sup> The DSU contained cells that were “lighted 24 hours per day,” which the plaintiff alleged disrupted his sleep and led to psychological problems.<sup>1</sup> The district court found the 24-hour lighting conditions to be unconstitutional, stating: “[t]here is no legitimate penological justification for requiring [inmates] to suffer physical and psychological harm by living in constant illumination.”<sup>1</sup> In *Huertas v Secretary Pennsylvania Dept of Corrections*, Hector Huertas made a similar claim: Huertas alleged that the 24-hour lighting within the corrections unit violated the Eighth Amendment’s prohibition against cruel and unusual punishment.<sup>2</sup> However, the Third Circuit Court of Appeals found that Huertas’ claim did not reach the threshold of being unconstitutional, noting that “not all deficiencies and inadequacies in prison conditions amount to a violation of a prisoner’s constitutional rights.”<sup>2</sup> Differences in the outcomes of these cases highlight the subjective nature of identifying and defining torture inflicted via sleep deprivation tactics and reveal a need for proper **liaising between medical and legal professionals** to ensure adequate protection of people experiencing incarceration.

## **Sleep and the Right to Health**

Sleep is an essential component of the body's homeostasis and physiological functioning. Quantifying sufficient duration and quality of sleep can prove difficult, as sleep patterns and needs vary not only between individuals but also for any given individual in response to aging, changes in routine, and physical demands. However, our understanding of sleep—its mechanics, cycles, and effects on the body—has improved dramatically over the last century, and thus our understanding of its converse—sleep deprivation—has concurrently grown deeper. As sleep is integral to health and the right to health has been recognized by numerous international governing bodies,<sup>3,4</sup> it follows that the purposeful deprivation of sleep violates the right to health though it is frequently used as a means of torture. Perpetrators often avoid accountability by justifying torture based on specific circumstances. Furthermore, the lack of a specific threshold of what constitutes sleep deprivation and the “justification” exemption as interpreted by some states present challenges in prosecuting it as torture. The ambiguity in legal definitions of torture, especially in the context of sleep deprivation, necessitates a careful examination of medical literature, existing laws, and international conventions to protect sleep as an essential human right and prevent its use as a means of coercion and abuse.

The World Health Organization defined health in its 1946 constitution as “a state of complete physical, mental and social well-being” and declared that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.”<sup>3</sup> As is common knowledge and as studied by numerous clinicians and scientists, optimal health is not possible without an appropriate quality and quantity of sleep (ie, proper sleep hygiene). Poor sleep hygiene is associated with cardiovascular disease, inattention, learning difficulties, mental health disorders, and numerous other medical problems in adults and children.<sup>5</sup> Sleep medicine experts consider good sleep to consist of 4 to 5 uninterrupted sleep cycles of light, deep, and rapid eye movement sleep.<sup>6</sup> While beyond the scope of this commentary, the **intricacies of these cycles** are what lead to the physiological restorative effects necessary for cognition and routine repair that the body performs, and, conversely, interruptions in these cycles lead to specific sleep disturbances and sequelae. Consequently, clinicians recommend 7 to 9 hours of sleep daily (preferably at night) and maintaining a consistent sleep schedule.<sup>6</sup> Sleep deprivation, whether intentional or unintentional, disrupts these processes, making it impossible for the body to function at its highest level.

## **Distinguishing Torture From Cruel, Inhuman, or Degrading Treatment**

Based on the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UNCAT), torture is characterized by 4 critical elements: (1) “severe pain or suffering” (either physical or mental), (2) intentionality of the perpetrator to deliberately inflict such pain, (3) a specific purpose (such as “obtaining from him ... information or a confession,” intimidation, or punishment), and (4) involvement of persons in an “official capacity.”<sup>7,8</sup> This definition has evolved to encompass various forms of harm, including prolonged mental harm or deliberately disrupting senses or personality.<sup>8,9</sup>

The Geneva Conventions, particularly Geneva Convention III of 1949, highlighted the prohibition of torture in conflicts and for individuals not actively engaged in hostilities.<sup>10</sup> President Ronald Reagan signed the UNCAT in 1988, and Congress enacted 18 USC §2340A in 1994 to comply with the Convention.<sup>11</sup> This statute applies only to acts of torture committed outside the United States, although there is “Federal extraterritorial

jurisdiction over such acts whenever the perpetrator is a national of the United States or the alleged offender is found within the United States, irrespective of the nationality of the victim or the alleged offender.”<sup>12</sup> The statute defines torture as specific acts intended to cause severe physical or mental pain,<sup>12</sup> omitting the original language about the purpose of harm, thereby introducing ambiguity and, as some have attempted to argue, a torture justification exemption.<sup>13</sup>

While the universally accepted UNCAT definition of torture involves the intentional infliction of severe physical or mental pain or suffering by a public official for a specific purpose,<sup>12</sup> other definitions have been offered. The Inter-American Convention to Prevent and Punish Torture offers a broader definition that does not necessitate severe pain and suffering.<sup>14</sup> In international humanitarian law, torture is not confined to public officials but can be committed by any individual.<sup>15</sup> Despite differing interpretations of torture, the UNCAT definition remains the core reference for defining torture. The UNCAT distinguishes between “torture” and “other acts of cruel, inhuman or degrading treatment or punishment” (CIDT) and *prohibits* torture completely while obligating states only to *prevent* CIDT.<sup>15</sup> Understanding the origins of these distinctions provides insight into the continued difficulty in reaching legal agreement on where the line is between them.

The UNCAT was initially developed in response to a UN General Assembly resolution. The Commission on Human Rights (now the Council on Human Rights) created a draft convention against torture to replace the 1975 declaration against torture,<sup>16</sup> which defined torture as an “aggravated and deliberate form of cruel, inhuman or degrading treatment or punishment.” To achieve this goal, the Commission on Human Rights established a working group to examine the distinction between torture and CIDT.<sup>16</sup> The working group concluded that while torture could be defined with reasonable precision, drafting a precise definition of inhuman treatment was impossible.<sup>16</sup> Additionally, because State Parties to the convention would be legally bound to incorporate its terms into their national criminal law, attaching these obligations to a vague concept like CIDT was deemed impractical.<sup>17</sup> Taking into account the Commission on Human Rights’ working group’s discussions, the recommendations of the European Commission of Human Rights (European Commission), and the European Court’s evaluations, the UN General Assembly adopted the definition of torture as outlined in the UNCAT in December 1984.

While the 1975 declaration against torture viewed torture as an aggravated form of inhuman treatment, the UNCAT clarified the distinction to be about purpose more so than severity. As such, Article 16 explicitly refers to “cruel, inhuman and degrading treatment or punishment which do not amount to torture” and only requires State Parties to “undertake to prevent,” rather than prohibit, such acts committed under their jurisdiction.<sup>7</sup> This distinction is significant, as the UNCAT mandates that States Parties establish judicial remedies for torture victims, assert criminal jurisdiction over acts of torture and prosecute or extradite its perpetrators, and prohibit the submission of all statements obtained through torture in legal proceedings.<sup>7</sup> None of these obligations apply to inhuman treatment.

The issue of the severity of pain or suffering caused by torture was actually addressed earlier, however. In the 1969 “Greek case” involving Denmark and other states against the Greek military government,<sup>18</sup> the European Commission was tasked with interpreting Article 3 of the European Convention, which prohibits torture or “inhuman or degrading

treatment or punishment.” The European Commission categorized Article 3’s prohibition into 3 parts: “inhuman treatment” was defined as treatment deliberately causing severe mental or physical suffering that is unjustifiable in the particular situation; “degrading treatment” was described as treatment that grossly humiliates a person before others or forces them to act against their will or conscience; and “torture” was described as inhuman treatment that serves a purpose, such as obtaining information or confessions or inflicting punishment, and is generally a more severe form of mistreatment.<sup>19</sup>

While the European Commission’s decision had a significant impact on the 1975 UN declaration against torture,<sup>20</sup> which also recognized torture as an aggravated form of inhuman treatment, the case of *Ireland v United Kingdom* in 1980 presented a challenge to the European Commission’s purpose-driven test. This case involved the use of 5 interrogation techniques—including sleep deprivation—by British security forces on Irish Republican Army suspects.<sup>21</sup> The European Commission concluded that the purpose of these techniques was to obtain information and unanimously ruled that they amounted to torture, stating that the systematic application of the techniques for this purpose resembled methods of systematic torture.<sup>21</sup> However, the European Court of Human Rights disagreed with the European Commission’s assessment. The European Court acknowledged that the techniques constituted inhuman treatment but did not consider them to be torture.<sup>21</sup> The European Court instead based its decision on a different interpretation of the distinction in Article 3 of the European Convention between torture and inhuman or degrading treatment, emphasizing that this distinction primarily hinges on the intensity of the suffering inflicted. According to the European Court, while the 5 techniques, when used together, undoubtedly amounted to inhuman and degrading treatment, they did not cause suffering of the specific intensity and cruelty associated with torture.<sup>21</sup>

Although both inhuman treatment and torture involve suffering, the European Commission emphasized that the purpose of the conduct is crucial in distinguishing between the two. It maintained that severe suffering might be justifiable in certain circumstances but that torture, with its additional purposeful element of obtaining information or confessions or inflicting punishment, can never be justified.<sup>21</sup> The European Court, however, argued that torture deserved a “special stigma” not attributable to other forms of inhuman or degrading treatment due to the intensity of suffering involved.<sup>21</sup> This distinction formed the basis of the court’s decision to classify the 5 techniques as inhuman treatment rather than torture.<sup>21</sup> In summary, the European Commission distinguished torture from CIDT by the purpose of the act, whereas the European Court distinguished torture from CIDT by the severity of suffering from, more so than the purpose of, the act.

Post *Ireland*, the distinction between torture and CIDT based on the severity of suffering led some states to argue that, while torture is forbidden, CIDT might be justified in exceptional circumstances.<sup>17</sup> Both torture and CIDT are forbidden by the UN Declaration of Human Rights (Article 5), UNCAT, the International Covenant on Civil and Political Rights (Article 7), and the European Convention on Human Rights (Article 3).<sup>7,22,23,24</sup> The *legal* distinction between torture and CIDT hinges on the *purpose* behind the acts (torture aims to obtain a confession, while CIDT does not have a specific purpose).<sup>25</sup> However, *medical and psychological research* have demonstrated that there is no significant difference between torture and CIDT from a psychological or neurobiological perspective.<sup>26</sup> This research has led some practitioners to recommend abolishing the distinction altogether.<sup>26</sup>

Thus, there is no justification for torture or CIDT, as the legal distinction between acts of torture and CIDT does not align with their psychological impacts. It is known that torture leads to false confessions and inaccurate information.<sup>27</sup> If it is not the purpose of the offender to obtain false and inaccurate information, then the only other plausible motivation behind the torture is to cause intentional and purposeful harm to a targeted individual, which, by definition, is torture and is illegal under domestic and international law.<sup>9</sup>

### **Sleep Deprivation as Torture**

Sleep deprivation is carried out in various ways: constant illumination, cold conditions, loud noises being played, constant and repetitive awakening, forced standing, and so on.<sup>28,29</sup> Although the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment has regularly declared that sleep deprivation is capable of amounting to torture, the threshold at which methods to cause sleep deprivation become torture is subject to interpretation.<sup>30,31</sup> Notably, the above conditions occurring in immigration detention centers in the United States have failed to be unanimously recognized as torture, despite various elements of torture—including duration, intentionality, and specific purpose—being behind their use.<sup>28</sup>

It should be noted that sleep deprivation occurs in numerous other circumstances that do not amount to torture. Around the world, work-life boundaries are blurred, as people are constantly on email and social media. Shift workers switch back and forth between day and night shifts. Many of us choose to forgo sleep for other activities despite knowing how poorly we may feel after insufficient or poor-quality sleep. But in all of these circumstances, we have at least limited agency to choose sleep. Persons subjected to sleep deprivation as a form of torture have no agency and no ability to modify their environments or habits to ensure sleep.

### **Prosecuting Perpetrators of Sleep Deprivation**

Due to certain qualifications contained in definitions of torture and lack of proper documentation of torture tactics, the prosecution of sleep deprivation as a form of torture has been largely unsuccessful.<sup>32</sup> Furthermore, findings in US cases prosecuting sleep deprivation as torture vary significantly. This variation may be explained by the exemption justification that arises under the UNCAT's and earlier conventions' distinguishing torture from CIDT, as exemplified below.

In the United States, sleep deprivation has been historically considered a form of torture since the case of *Ashcraft v Tennessee* in 1944.<sup>33</sup> The individual in this case was subjected to 36 hours of bright lights that caused sleep deprivation, and the court acknowledged it as both physical and mental torture, citing and quoting from an earlier report: "It has been known since 1500 at least that deprivation of sleep is the most effective torture and certain to produce any confession desired."<sup>34</sup> Numerous studies have corroborated that confessions obtained under these conditions are often false and thus of little utility.<sup>33,35</sup>

Legal cases, such as *Keenan v Hall*<sup>36</sup> and *LeMaire v Maass*,<sup>1</sup> have highlighted unconstitutional aspects of subjecting individuals to constant illumination, emphasizing the psychological harm caused by disturbing sleep patterns and exacerbating preexisting mental disorders. In *LeMaire*, Chief Judge Owen Panner noted that "[t]here is no legitimate penological justification for requiring plaintiff to suffer physical and psychological harm by living in constant illumination. This practice is unconstitutional."<sup>1</sup>



However, the War Crimes Act, enacted to prosecute violations of the laws of war, has not been effectively utilized for prosecuting acts of sleep deprivation as torture, despite its provisions covering international and non-international armed conflicts involving US citizens.<sup>37</sup>

Challenges persist in fully recognizing and prosecuting sleep deprivation as a form of torture due to varying legal interpretations within the judicial system. Notably, there have been instances in which courts, under the guise of penological purpose, have eroded the authority of cases concerning the prosecution of sleep deprivation as torture, which have laid much of the groundwork for how torture and other acts of CIDT are prosecuted.<sup>38</sup> Violation of the Eighth Amendment's prohibition against cruel and unusual treatment might be overlooked if a government entity deems the practice justified by emphasizing that the penological purpose must specifically align with the prisoner's situation.<sup>38</sup>

Additionally, the lack of a definitive sleep deprivation threshold for torture set by higher courts has contributed to ambivalence in addressing the issue. Despite medical evidence affirming sleep deprivation's cruelty and inhumanity, the absence of a clear legal boundary has left room for interpretation that potentially overlooks violations of the Eighth Amendment in instances of extreme sleep deprivation. In a petition for a *writ of certiorari*—a petition by a higher court to a lower court to review a case—to the United States Court of Appeals for the Ninth Circuit, petitioner Neil Grenning noted: "It's an easy path to ambivalence, despite undisputed medical evidence that it's 'cruel and inhumane,' because no higher court has set a threshold. No court has said, 'This is too much, this is wanton infliction violating the Eighth Amendment.'"<sup>38</sup> Additionally, as Hector Heurtas' case exemplifies, evidence of intentionality can be difficult to prove, making the practice insidious.<sup>2</sup>

While some international conventions have recognized and condemned sleep deprivation as a method of torture or abuse, prosecutions specifically targeting sleep deprivation as a stand-alone crime have been less common. In some cases, instances of sleep deprivation have been included as part of broader charges related to torture or ill treatment, but direct prosecutions solely focused on sleep deprivation are relatively rare in international courts or tribunals. Instances in which sleep deprivation was categorized as torture include reports on Indonesia, Iran, Jordan, Libya, Saudi Arabia, Turkey, and Pakistan, where it was explicitly classified as a "common torture method" or included among other recognized torture methods like loud music.<sup>32</sup> Despite sleep deprivation being acknowledged as a prevalent method of psychological torture, finding corroborating documentation of these practices has hindered its adequate recognition by courts and quasi-judicial bodies like UN treaty bodies. In fact, Appendix M of the Army Field Manual for Human Intelligence Collector Operations No. 2-22.3 continues to permit isolation, sensory deprivation, and sleep deprivation, which can constitute torture or CIDT as defined by UNCAT and US law.<sup>39</sup>

### **Legal Definitions and Clinical Assessment**

To enable more uniform interpretation of sleep deprivation as torture, medical professionals must provide clarity regarding the extent of pain and suffering experienced by an individual who underwent intentional sleep deprivation to assist courts in assessing whether a specific instance of sleep deprivation meets the threshold of torture. The American Medical Association states that "[a]s citizens and as professionals with specialized knowledge and experience, physicians have an obligation to assist in

the administration of justice.”<sup>40</sup> To successfully fulfill this obligation, physicians may testify as expert witnesses in cases prosecuting sleep deprivation as torture. This testimony would serve to show that prolonged sleep deprivation does in fact deserve the “special stigma” of torture due to the very real physical, mental, and emotional impacts it has on its victims.

In a court setting, a medical expert testifying to establish that sleep deprivation amounts to torture would provide a detailed overview of the case, including the circumstances surrounding the sleep deprivation experienced by the individual, such as its duration, the context in which it occurred, and the techniques used to cause sleep deprivation. The expert would additionally discuss the methods used to assess the physical and psychological effects of sleep deprivation on the individual. This discussion might include descriptions of physical examinations, medical tests, and psychological evaluations conducted to evaluate the individual’s health status and well-being. The expert would present their findings, highlighting any physical or psychological symptoms observed in the individual as a result of sleep deprivation. The gold standard for conducting and documenting such forensic evaluations is the Istanbul Protocol.<sup>41</sup>

Based on their findings and expertise, the expert would provide their opinion on the severity of the effects of sleep deprivation on a given individual. The medical expert’s opinion would allow the court to understand the severity of the specific sleep deprivation a person endured, its effect on a given person’s physiology, and the sequelae that resulted, thus providing clarity to the courts as to whether or not a given individual’s experience meets the threshold for torture.

### Conclusion

International definitions of torture, such as that of the UNCAT, emphasize severe pain or suffering, intentionality, specific purpose, and official capacity. The justification exemption for CIDT used in the United States<sup>17</sup> is a false argument. There is no significant difference between torture and CIDT from a psychological or neurobiological perspective. Torturing individuals through sleep deprivation or any other means of cruel, inhumane, or degrading treatment as a means to glean confessions or important information does not yield reliable information. And since that information has no value (which, even if it did, we feel would not justify the torture), then the only purpose of the torture or CIDT is to intentionally harm someone, which, by definition, is not a justifiable exemption.

Courts internationally and in the United States have recognized sleep deprivation as cruel and unusual punishment, constituting torture. Sleep deprivation, achieved through techniques like prolonged interrogations and acoustical bombardment, causes severe mental and physical consequences, including increased anxiety, impaired cognitive function, and increased cardiovascular risk. Particularly in light of the subjective nature of mental suffering, the frequent absence of obvious physical evidence, and the purposeful lack of documentation of such evidence by the perpetrators, it is imperative that **medical experts bridge the gap** between science and the law, testifying to the specific negative effects of sleep deprivation on a given person and thus clarifying thresholds at which maltreatment amounts to torture.

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**STATE OF THE ART AND SCIENCE**

**What Should a Public Health Approach to Sleep Look Like?**

Galit Levi Dunietz, PhD, MPH, Erica C. Jansen, PhD, MPH, and Ronald D. Chervin, MD, MS

**Abstract**

Sleep is essential for a healthy, productive life, but access to sufficient and quality sleep is not universal. Sleep equity is influenced by both pathological and nonpathological sources. This article considers nonpathological determinants of adequate sleep, defines 3 features of sleep insecurity, and suggests how to promote sleep literacy to remove some barriers to adequate sleep, promote sleep equity, and improve individual and community health and well-being.

**Sleep and Public Health**

Air, food, and water are essential for human survival, and access to each is considered a fundamental human right. No less essential for survival is sleep, and insufficient or poor-quality sleep—like insufficient or poor-quality air, food, or water—is associated with severe health consequences.<sup>1,2,3,4,5,6</sup> Therefore, sleep, too, has been considered a fundamental human right.<sup>7,8</sup> However, public health efforts to ensure sufficient quality of air, food, and water and thereby avoid serious health problems have traditionally dwarfed attention to adequate sleep. Moreover, adequate sleep is not universally accessible, as many people endure circumstances beyond their control that create substantive sleep inequities and disparities.<sup>9</sup> As a result, adverse health and social consequences ensue, often without the realization of those affected.<sup>10</sup> Public health policies and legislation have scarcely kept pace with the rapidly expanding but still young science of sleep and biological rhythms. The passage of California's law regarding later school start times for high school students is a notable exception.<sup>11</sup>

The first half of this manuscript will describe the concepts of *sleep insecurity* and *sleep deserts*, terms that help to illuminate inadequate sleep as a social justice issue. Although many sleep determinants may seem familiar, they are seldom discussed in the context of inequity, taken to mean absence of justice or fairness. The second half of this manuscript will propose key public health policies that could improve sleep equity and secure better health, quality of life, and well-being in a tangible manner and for sizeable segments of the population.

### **Sleep Insecurity and Sleep Deserts**

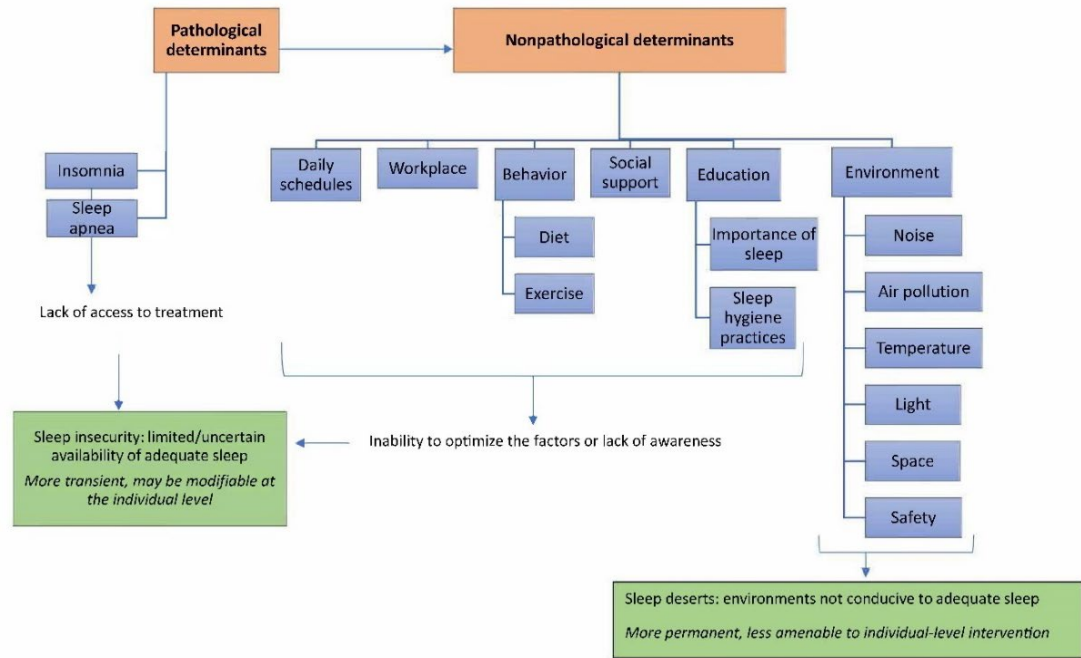
The **right to adequate sleep**—sufficient in amount and quality—is often put at risk by multiple barriers that can be transient or persistent.<sup>12</sup> The concept of sleep insecurity refers to the “limited or uncertain availability of adequate sleep,” whether short-term or long-term.<sup>13</sup> A related concept, sleep deserts, refers to environments that “are not conducive to adequate sleep health.”<sup>14</sup> Whereas sleep insecurity may be transitory, sleep deserts inflict chronic, poor sleep on their residents. Whether barriers to adequate sleep health are mild and transient or rampant and persistent, they often have an uneven distribution and intensity across communities, environments, and societal circumstances.

*Sleep deserts.* Sleep deserts exist in socioeconomically disadvantaged neighborhoods—for example, where busy transportation routes too frequently cause noise and air pollution that prevent good-quality sleep.<sup>15</sup> Beyond neighborhoods, sleep deserts can extend into a college dormitory where students on completely different sleep schedules engage in late-night activities that prohibit sound sleep.<sup>16</sup> Communities plagued by war, crime, or other threats of violence do not offer safety during an unconscious state of sleep and can also create sleep deserts.<sup>17,18</sup> Global warming has raised fears that some regions are becoming too hot to support human life, with the result that high nighttime temperatures—without air conditioning, which remains out of reach for many—threaten sleep quality that depends on reasonably cool surroundings.<sup>19</sup>

*Sleep insecurity.* In contrast to persistent exposure to sleep deserts, many situational realities beyond the sleep environment can contribute to sleep insecurity. At a school where pressures to succeed cause excessive anxiety, students can experience sleep insecurity. Work environments—in medicine, the military, and factories, for example—can require such excessive working hours that sleep insecurity can emerge.<sup>20,21</sup> Intermittent shift work repeated weekly creates sleep insecurity, as no human circadian rhythm can adapt effectively to many wake-sleep schedule changes every few days.<sup>22</sup> Even if workplace requirements do not technically preclude adequate sleep or alignment with the circadian rhythm, work-related stress and anxiety can still foster sleep insecurity. All these situations, beyond the impact of physical environments, have similar potential to create inequities in sleep health.

Human behaviors can also give rise to sleep insecurity. Alcohol consumption at night, caffeine consumption later in the day, adoption of a highly variable sleep schedule, or heavy meals near bedtime<sup>23</sup> are all detrimental to good sleep quality. A summary of the determinants of sleep insecurity and sleep deserts is illustrated in the Figure.

**Figure.** Determinants of Sleep Insecurity and Sleep Deserts



*Prevalence of sleep disorders.* Large proportions of the population suffer from undiagnosed sleep disorders and often have symptoms for decades.<sup>24</sup> Insomnia symptoms affect about 30% to 40% of the population at any one time, and specific **insomnia disorders** have a prevalence of 5% to 10% in adults.<sup>25</sup> Obstructive sleep apnea affects more than half of individuals with diabetes, and symptoms of restless legs syndrome affect up to 15% of adults.<sup>26,27</sup> Few individuals emerge from childhood without having had sleep problems. Yet, in many cases, no medical assistance is sought, and only ineffective medical assistance is provided. Despite the pervasiveness of sleep problems, sleep medicine occupies only a few hours in a typical 4-year medical school curriculum; most medical textbooks devote scant numbers of pages to sleep disorders; and the ratio of board-certified sleep medicine physicians to people even in the United States, where they are more common than in many other countries, is 1:43 000.<sup>28,29,30,31</sup>

### Fundamental Determinants of Sleep Inequity and Potential Solutions

Inequities in sleep insecurity and sleep deserts are multifaceted and cannot be easily addressed by any single set of public health policies. However, many inequities do share at least 1 of 2 key underpinnings. The first is limited personal financial resources, which can be insufficient for an individual to live in a quiet neighborhood, ensure a secure sleep environment, avoid the necessity for shift work, access a healthy diet, or see a physician familiar with sleep disorders. The imperative to ameliorate poverty and socioeconomic challenges has long motivated compelling arguments to do so by many experts other than sleep health specialists, and yet the solution is not likely to be found easily or soon.

The second fundamental underpinning of inequities in sleep health, however, is lack of critical, relevant education about sleep health. Importantly, the solution—sleep health literacy—may be achievable much more readily than resolution of socioeconomic

disparities. Sleep health literacy is a first, key step to improving sleep for people who suffer from sleep insecurity and who live in sleep deserts. Importantly, education efforts must focus not only on individuals and health care professionals but also on school administrators and policy makers who can alleviate some of the barriers to adequate sleep.

*Individual-level measures.* At the individual level, education for children, their parents, and other adults about the importance of a simple concept—sufficient sleep, of good quality, on a regular basis—is astoundingly nearly completely absent from the curricula and agenda of schools, public health efforts, health literacy programs, relief agencies, health insurance companies, and government-run health programs in the United States and globally. Whereas nutrition and exercise programs are nearly universal experiences in schools, starting at early ages, teaching about the importance of healthy sleep is often excluded. Of note, the increasing focus on sleep health content in mass media and social media in recent years is welcome but does not represent an organized educational effort of the magnitude necessary to make a positive impact on sleep insecurity and sleep deserts. Moreover, media content should emphasize the need for 7 to 9 hours in bed nightly for most adults and considerably more for children and teens.<sup>32</sup> Little time is spent on the importance of quiet, dark, comfortably cool, and physically and mentally secure sleep environments. In fact, many young people assume that sleep time is infinitely compressible, like a sponge, and that it can accommodate any exigencies that demand more time spent awake. Many individuals are not aware that lost sleep usually cannot be made up entirely or that chronic **sleep deprivation** can have serious, even life-shortening, consequences.<sup>33</sup> Many do not appreciate the enormous risk to productivity, social interactions, quality of life, and well-being of sleep disturbances.

Awareness of sleep health and the basics of sleep medicine is also necessary for all clinicians who routinely provide wellness and sick visits,<sup>28</sup> as sleep disturbances are often unreported and undiagnosed but carry significant implications for overall health.<sup>33</sup> During routine visits, screening for poor sleep hygiene could help identify patients who may be at risk for poor sleep health.

*Societal-level measures.* Beyond individual-level education, widespread implementation of government- and institution-supported lifelong education about the importance of healthy sleep and feasible steps to achieve it would reduce sleep inequities even in sleep deserts. The aim of this sleep health literacy campaign should be to change a culture that devalues sleep and, moreover, celebrates the implied dedication, motivation, or strength of those who defy natural sleep needs through use of caffeine, force of will, or other means. These programs should be available in all communities across all socioeconomic levels. However, their implementation in underserved communities that endure inequities in wealth, safety, education, and health may have the highest impact and may merit prioritization. The earliest beginnings of such programs already exist. Sweet Dreamzzz® for Early Childhood, now part of the Pajama Program,<sup>34</sup> is a nonprofit organization established in the early 2000s in Detroit by a nurse, Kathleen Donnelly, who found children sleeping in the hallways outside their classroom in an inner-city elementary school. In the years since its establishment, the organization has delivered a half-day of sleep education to more than 70 000 children and their families and distributed sleep essentials.<sup>35</sup> A preschool curriculum for teachers with daily reinforcing teacher-administered lessons for 2 weeks after the day of intervention was found to have lasting impact in one study of Head Start programs in



Michigan,<sup>36</sup> but not in other Head Start programs in New York State.<sup>37</sup> This effort, though, developed and administered mainly by volunteers with only limited philanthropic, foundation, or National Institutes of Health funding, is an example of what could and should grow into a nationwide mandate at all public schools.

Despite strong advocacy and persuasive data, school start times in middle and high schools across much of the United States are still before 8:30 am. Parents, teachers, and school administrators often oppose changes likely to benefit the sleep of many students, as well as their academic and athletic performance, with negligible impact on after-school activities.<sup>38</sup> In 2019, California became the first state to pass a law requiring all high schools and middle schools to start after 8:30 am and 8 am, respectively, which provides a model for other states to follow.<sup>11</sup> Education campaigns that reach stakeholders should be part of public health efforts to improve the overall health, well-being, and academic performance of sleep-deprived teens and provide them with sleep security.

At the institutional level, inclusion of sleep health information in **medical school curricula** and continuing medical education activities to highlight symptoms, risk factors, and consequences of poor sleep has the potential to help ameliorate sleep insecurity and sleep deserts. Cost-effectiveness research and dissemination of its results could also help to convince health plan administrators that sleep health literacy, screening programs, health promotion programs, and sleep medicine services are win-win opportunities. Indeed, cost-effectiveness research has shown that diagnosis and treatment of obstructive sleep apnea likely saves insurers considerable downstream health care expenditures.<sup>39,40</sup> Similarly, the enormous economic burden of insomnia, the most common sleep disorder among adults, would be significantly reduced with treatment, according to several studies.<sup>41</sup> Financial benefits to society, insurers, and individuals thus would be likely if sleep disturbances and disorders were reduced.

At the corporate level, education of employers about individual chronotypes and losses in productivity of sleep-deprived staff could lead to policies that improve sleep health for employees and, at the same time, enhance on-job effectiveness, well-being, and profits.

Effective education programs would be a first step toward major policy changes that could take years to be envisioned, formulated, and realized before sleep deserts are largely eliminated. Conceivable examples, however, include solutions that would address some of the more obvious disruptors of sleep from a public health perspective. For example, sleep health education for policy makers could lead to incentives for sleep security-enhancing features in new low-income housing, including safety features, noise abatement, and temperature control, which should be part of housing codes to the same extent that safe water and sewage are required. Sleep health-savvy policy makers could also conceivably reduce noise in neighborhoods along train tracks by enforcement of the maximum volume level for locomotive horns (96 decibels),<sup>42</sup> by modified train schedules between 12 am and 5 am, and by incentives for residents of sleep deserts to implement effective soundproofing.

## **Conclusion**

As public health advocates, we believe that education—sleep health literacy—should be a key initial priority in any long-term public health strategy to address sleep insecurity, sleep deserts, and inequity in sleep health.<sup>43</sup> For local, state, and national government structures, education of staff at all levels with responsibility for schooling and public

health would ensure well-informed choices and policy making. At the corporate and institutional level, education of employers could promote higher productivity, improved mood, and profits. At the individual level, people who suffer from sleep inequities rarely realize that this is a fundamental problem. A baseline level of sleep health literacy would enable people to be better self-advocates, to realize that healthy sleep is a key part of healthy wakefulness, and to make best use of any available resources to counter a substantial list of threats to their personal sleep security.

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Dr Chervin reports being a *pro bono* board member and president-elect of the International Pediatric Sleep Association, consulting for Eli Lilly, receiving royalties from UpToDate, and being named in patents. Drs Dunietz and Jansen disclosed no conflicts of interest.

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## AMA Journal of Ethics®

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### POLICY FORUM: PEER-REVIEWED ARTICLE

#### We're All Healthier Under a Starry Sky

Mario E. Motta, MD

##### Abstract

A star-filled sky has long been a source of awe and inspiration, and its loss adversely affects human, nonhuman, and environmental health. In one generation, this majestic nighttime overstory has been lost due to national and international overuse of light-emitting diodes lighting. This article canvasses ill health effects of excessive light at night. Blue wavelengths of light are damaging to many forms of life, and glare from unshielded light compromises road safety and infiltrates bedrooms, suppressing melatonin production, undermining sleep quality and duration, and exacerbating susceptibility to many kinds of illness.

*The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

##### Adverse Health Effects of Light at Night

For all of human existence, people have been inspired by the beauty of the night sky and marveled at the majesty of the Milky Way above their heads. Yet, in just one generation's lifetime—a blink of an eye—ever present and increasingly omnipresent outdoor light at night (LAN) has hidden this nighttime spectacle behind a veil of excessive outdoor illumination.<sup>1,2,3</sup> This tragic loss is especially prevalent in industrialized nations, where very few can now see the sky in all its majesty. With the proliferation of very efficient, inexpensive, and brighter light-emitting diodes (LED) lighting, this trend has markedly accelerated over the past few years, along with the harms of excessive blue LED emission.<sup>2,4,5,6</sup> In particular, there are significant adverse health effects of excessive outdoor LAN that have been documented by a plethora of studies over the past 30 years.

*Suppression of melatonin production.* There are, of course, strong economic and climate-related arguments for using LED street lighting, such as energy efficiency, since LED lighting uses less energy than incandescent lighting. However, not all LED lighting is optimal. Some LED lighting fixtures produce excessive blue light emission, which is harmful to human health as well as the environment. “Cool” color-correlated temperature (CCT) LED streetlights have a spectrum that spikes in the blue wavelengths, which are more effective at suppressing melatonin production during the night than red wavelengths.<sup>7</sup> CCT LED lighting above 3000 Kelvin (K) has excessive blue light (about

21% blue for 3000 K, rising to 32% blue for 4000 K). By comparison, 2700 K LED lighting is around 15% blue.<sup>8,9</sup> It is slightly amber in color but not as harsh to the human eye. In dense urban environments where most people live, unshielded streetlights shine into bedrooms at night, and even small amounts are enough to suppress melatonin production.<sup>7,10</sup>

The American Medical Association (AMA) led the way by alerting the world to the dangers of excess LAN back in 2012 with a report titled “Light Pollution: Adverse Health Effects of Nighttime Lighting” and a second report in 2016 titled “Human and Environmental Effects of Light Emitting Diode (LED) Community Lighting.”<sup>11,12,13</sup> Since then, 16 states and many cities and towns across the United States and in Europe have adopted the AMA recommendation to keep outdoor lighting below 3000 K.<sup>14,15</sup> Some companies, such as Apple, have even incorporated this recommendation in its products; the iPhone and iPad night shift setting limits blue **light from screens after sunset**.<sup>16</sup> However, implementation of the AMA recommendation to date has been sporadic in other companies and products.

**Glare.** In addition to suppressing melatonin production, improperly designed and poorly shielded light fixtures can result in glare and create a road hazard condition. Indeed, “glare is the most common health safety problem resulting from poorly designed outdoor lighting,”<sup>17</sup> as intense blue LED lighting leads to discomfort and disability glare. As I have noted elsewhere:

Over time, calcifications build up in the lenses of our eyes, which eventually develop into a cataract. These calcifications and other lens and eye imperfections scatter light in a similar fashion to a dirty windshield. This effect grows more severe with age, and is the primary reason why the elderly have a difficult time driving at night under poorly designed street lights.<sup>17</sup>

Recognizing that our streets could be safer places at night, the AMA adopted a policy in 2009 that urges full shielding for all public street lighting.<sup>18</sup>

Glare can be greatly mitigated by proper design, shielding, and installation so that no light shines above 80 degrees from the horizontal. The visual hazard posed by these very intense point sources is further magnified by cooler CCT LEDs, because blue light scatters more in the human eye than warmer wavelengths, leading to increased disability glare.<sup>8,19</sup>

It is most unfortunate that some car headlights are manufactured with CCT as high as 6000 K. Such a high CCT blinds oncoming drivers and is a severe safety hazard. The energy efficiency of 3000 K lighting is “virtually the same” as that of 4000 K lighting.<sup>20</sup> due to the coatings used, and this very small efficiency loss is more than compensated for by light emission that is more pleasing and environmentally friendly.

**Cancer.** There are now voluminous peer-reviewed articles showing a higher risk of hormonally linked cancers, such as breast and prostate cancers, with melatonin suppression.<sup>4,21,22,23,24,25,26,27,28,29</sup> Higher risk of thyroid and pancreatic carcinoma associated with LAN has also been reported in the literature.<sup>30,31,32</sup> The root problem lies in the disruption of **circadian rhythmicity** through suppression of melatonin production by the pineal gland. We evolved to have melatonin rise at sunset, but, in the modern world, melatonin production is delayed until bedtime and lights are out. Perniciously, however, even at bedtime, light penetrates into bedrooms in urban and suburban areas, further suppressing melatonin production. Melatonin has been shown to be an

important adjuvant to the human immune system. During sleep, our immune system attacks and removes abnormal cells that are produced daily during normal cell division. If the immune system is reduced in efficiency by lack of or diminished melatonin production, then there exists an incrementally higher chance that an abnormal cell will escape detection and may proliferate as a cancer.<sup>33,34</sup>

One particularly large, landmark study published in 2017, entitled “Outdoor Light at Night and Breast Cancer Incidence in the Nurses’ Health Study II,” followed 109 672 nurses from 1989 through 2013.<sup>21</sup> Linking data from satellite images of Earth taken at night to the zip code of the residential address of each study participant, the researchers divided the participants into 5 cohorts. Women in the top fifth of exposure levels of outdoor LAN had an estimated 14% increased risk of breast cancer during the study period compared with women in the bottom fifth of exposure. There are now at least 20 peer-reviewed papers in the world literature that all show consistent and similar results.<sup>4,21,22,23,35</sup> Artificial LAN has also been associated with sleep disturbances, depression, psychiatric disorders, and obesity with a subsequent increased incidence of diabetes.<sup>18</sup>

### **Adverse Environmental Effects**

The detrimental effects of LAN are not limited to humans, as nearly all animals and plants are also adversely affected by it. There now exists a burgeoning and robust literature documenting the environmental damage caused by excessive outdoor LAN. Birds, insects, and mammals are especially hard hit, as I have described elsewhere.

Some 60 per cent of animals in the wild are nocturnal, and adversely affected by exposure to nighttime outdoor lighting. Many birds are known to navigate by the sky at night, and get confused by excessive lighting, leading to large numbers of bird kills. Many insects need a dark environment to procreate, the most obvious example being fireflies, that cannot ‘see’ each other because of light pollution. Many other beneficial insects are drawn to the blue-rich lighting, and circle under them until they become exhausted and die. Unshielded lighting on beach areas has led to a massive drop in turtle populations. Turtles are programmed to head to the reflection of the moon on the nearby water. The hatchlings are disoriented by artificial light and sky glow, preventing them from reaching the water safely. Even bridge lighting that is ‘too blue’ has been shown to inhibit upstream migration of certain fish species such as salmon returning to spawn. The growth of light pollution along the borders of the national parks in the USA spills light into the parks, leading to detrimental effects on their bioenvironment. Recognizing the adverse impact on nocturnal species, parks now require minimal lumens and shielded lighting whenever installed.<sup>36</sup>

Partly due to excess LAN, we are witnessing a massive decline in species across the globe. The precipitous decline in insect populations is particularly dire, and it has been stated in *Nature Ecology and Evolution* that we are in the midst of an “insect apocalypse,”<sup>37</sup> with a 45% decline in insect populations in the past 40 years.<sup>38</sup> This decline has ominous implications for the food supply of many species, such as birds, and for pollination of our food supply. For example, marine plankton live in the dark but migrate every night to the surface waters to feed on algae near our shores. However, plankton are extremely averse to even the faintest rays of light and thus do not migrate up to feed near light-polluted shores. This is a dire problem, as plankton are the base of the ocean food chain, and their disappearance also allows algae to proliferate near our shores.<sup>39,40</sup>

Even plant life is adversely affected by LAN. Trees that do not shed their leaves on time in late fall because they are fooled into thinking that the daylight hours are not waning have a shortened lifespan from the environmental stress.<sup>41</sup> Open fields of soybeans



have differential maturation times if part of the field is exposed to LAN, complicating farmers' harvesting of the crop.<sup>41,42</sup>

### Conclusion

Thus, in a very real sense, the loss of a starry sky is directly correlated with human health risk and environmental damage. The fewer stars you see when you look up can be a marker of that risk. This is not to say that the loss of visibility of stars in the sky is causally related to human and environmental health, of course, but there exists a correlation between them that can be quantified. It behooves us to restore balance between natural and outdoor, built environments. To do so is not difficult: use outdoor lighting responsibly; use outdoor LAN only where needed, for the time needed; and don't overlight. Shield light sources from direct eye contact, and especially avoid outdoor nighttime blue light emission. These commonsense steps, if implemented, will lead to a healthier environment, help restore nature's balance, and maybe even gain back a starry sky to inspire all of us once more.

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## AMA Journal of Ethics®

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### How Should We Advance Sleep Stewardship?

Jeremy A. Gallegos, PhD

##### Abstract

Sleep is a vital but overlooked and undervalued part of our overall health and well-being. Striving to optimize productivity and meet numerous daily demands often means that sleep is not prioritized. As sleep stewardship's importance gains wider recognition, clinical and ethical management of sleep resources and practices will likely be key features of health professionalism. This article considers how sleep stewardship should be advanced as a clinical, ethical, and cultural priority.

##### Sleep as a Human Right

Sleep, a fundamental biological necessity, is frequently undervalued and neglected in contemporary society, a trend that intensified during the pandemic.<sup>1</sup> Despite the consensus that basic human rights encompass necessities such as food, shelter, and clothing,<sup>2</sup> sleep is seldom recognized as a basic human right.<sup>3</sup> While rest from work is viewed as a basic human right by the Universal Declaration of Human Rights,<sup>2</sup> the prevailing societal attitude equates **sleep deprivation** with productivity and success, epitomized by the common adage, "I'll sleep when I'm dead." This perspective, however, can have severe implications for our health and well-being. This article examines the concept of "sleep stewardship," or the responsible and ethical management of sleep resources and practices. Here, I scrutinize sleep stewardship from cultural, clinical, and ethical viewpoints, arguing for a comprehensive approach that takes into account individual, societal, and environmental factors influencing sleep quality and quantity. By promoting sleep stewardship, I aim to enhance health outcomes and foster more sustainable lifestyles.

##### Sleep Practices

Although sleep is a universal physiological requirement, different cultures have different sleep practices and attitudes toward sleep that are influenced by various factors, such as technology, work, and socioeconomic status.<sup>4,5</sup> Technology has enabled unprecedented levels of communication and interaction, but it has also created **distractions and temptations that delay sleep**. Work demands and incentives can motivate people to forfeit sleep for productivity and income. Socioeconomic status can affect the accessibility and quality of sleep resources and practices, including comfortable beds, quiet environments, and regular schedules. These cultural factors shape not only sleep behaviors but also the expectations and preferences of individuals

and societies regarding sleep.<sup>4</sup> Some might view sleep as a privilege or a luxury, while others might view it as a necessity or a burden.<sup>5</sup> The former might fear missing out on socioeconomic opportunity and the latter might lose sleep out of necessity, for bare survival.

These individual sleep habits can become social problems. Unlike other basic survival needs, sleep is inherently an internal resource, but it is not always protected. It is not a resource to be hunted for or gathered. It can be independent of other resources. Yet the negative impacts of sleep deprivation extend beyond the individual to the larger society through a variety of cognitive errors, for example. Sleep stewardship as the responsible and ethical management of sleep resources requires practices that respect the dignity and well-being of oneself and others. As discussed later, it calls for a holistic approach that considers the individual, social, and institutional factors that influence sleep quality and quantity.

### **Sleep Deprivation**

A lack of sleep hygiene, or proper sleep environment and behavior, has resulted in individuals who are more than fatigued. There is in fact good evidence of higher mortality rates because of lost sleep, which is a universal concern. Specifically, in the past decade, several studies have linked duration and quality of sleep to longevity and general well-being.<sup>6</sup> Moreover, multiple studies conclude that lack of sleep can result in cognitively impaired performance likened to performing under the influence of alcohol.<sup>6</sup> Physically, lack of sleep can result in heart conditions and other diseases.<sup>7</sup> In general, sleep deprivation can have grave consequences for physical, mental, emotional, and social health, including increased risk of cardiovascular diseases, diabetes, obesity, depression, anxiety, impaired cognition, memory loss, poor judgment, reduced creativity, low mood, irritability, social isolation, and conflict.<sup>6</sup> These adverse results can be seen in the workplace in productivity losses and the like.<sup>7</sup> Outside of the workplace, lack of sleep results in fatal accidents like motor vehicle crashes.<sup>7</sup>

Sleep stewardship can prevent or mitigate these effects by enhancing our immune system, metabolism, brain function, mood regulation, learning capacity, creativity, problem-solving skills, emotional intelligence, social skills, and interpersonal relationships. Promoting sleep stewardship thus can improve health outcomes and well-being for individuals and communities. Sleep stewardship is not only a need but also a unique resource and right that warrants our attention and action. Sleep, unlike food and shelter, is an internal resource that can be renewed without “cost.” The cost to exercise the right to sleep is to take time to do so. To provide for a right to sleep is to allow individuals to practice sleep hygiene, which entails 8 hours of uninterrupted time for most people to rest and unwind.

### **Ethical Considerations in Sleep Stewardship**

Personal responsibility is intertwined with social responsibility for the protection of sleep time and the provision of an environment conducive to sleep health. But should an individual be held accountable by society for their lack of sleep? If so, who polices this behavior? Moreover, is it the prerogative of society to provide equal access to time for and environments conducive to sleep health? These issues come to loggerheads when lack of sleep risks impaired behaviors that threaten individual and communal health.

Sociopolitical recognition of sleep as a right presents a conundrum. Is sleep a positive right that mandates provision or a negative right that calls for the elimination of barriers



to its access? This same conundrum applies to the right to have other survival needs, such as food, satisfied. If food is deemed a positive natural right, it implies an obligation for its provision.<sup>8</sup> However, within the current sociopolitical-cultural milieu, food is categorized as a negative right wherein no constraints are imposed on legally procuring food for survival.<sup>9</sup> In fact, in some cases, withholding access to food is a weaponized version of negative rights. This dichotomy between positive and negative rights underscores the difficulty of ensuring proper sleep behaviors and environments. On the one hand, an individual should be accountable for their own sleep behavior, but there is no barrier to prevent some from choosing to forgo sleep for entertainment or work. On the other hand, that some individuals forgo sleep because they *must* work or lack access to a healthy sleep environment indicates that sleep as a negative right is not powerful enough. As a potential positive right, the capacity for sleep must be provided for individuals through protected time for sleep and access to a safe environment.

While it might seem absurd to need to protect sleep as a basic human need, it is key to sleep stewardship. Legitimately, for example, parents do oversee the sleep schedule of their minor children, which is to be expected. We must then ask, *Should physicians and the community as a whole take measures to protect time and environments for sleep?* This provision entails ensuring that individuals have sufficient time to rest and prepare for sleep, followed by uninterrupted sleep duration. The remaining challenge for many is that **equal access to sleep** necessitates not only time but also financial and other resources.

### **Promoting Sleep Stewardship**

Advocating sleep stewardship necessitates a comprehensive approach that considers the social, institutional, and individual factors influencing sleep quality and quantity. At the social level, raising awareness about the importance of sleep for health and well-being, challenging stereotypes associated with sleep deprivation or enhancement (such as that an individual sacrifices sleep for fear of missing out or indulges in so much sleep as to be considered slothful), supporting each other in developing healthy sleep habits, and respecting each other's sleep needs and preferences are crucial. At the institutional level, advocating for policies that support sleep rights, such as limiting work hours, providing flexible schedules, creating nap rooms, regulating sleep-enhancing technologies, and ensuring access to affordable and quality sleep resources and services are necessary. Consistent with the spirit of the "right to rest,"<sup>2</sup> safeguards should be put into practice, such as paid vacation, to protect that right. Such policy changes can only approach an equitable distribution of access to healthy sleep resources but cannot ensure it completely. While nearly every nation could endorse limited work hours and rest, not all countries have access to clinical studies necessary to treat sleep dysfunctions. For individuals, the best strategy for sleep promotion is a consistent routine. By setting a regular sleep schedule, individuals can organize other practices around it that promote sleep health. For example, specific exercise routines can be scheduled and use of digital screens be decreased hours before bedtime. Additionally, ceasing caffeine intake 9 hours before bedtime is recommended to increase sleep time and efficiency. However, personally protecting a time and space for sleep will go long way toward improving sleep outcomes.<sup>6</sup>

### **Conclusion**

This article has examined sleep stewardship—the responsible and ethical management of sleep resources and practices—from clinical, ethical, and cultural viewpoints, emphasizing the importance of sleep as not only a need but also a right. I have argued

that sleep stewardship necessitates a comprehensive approach that considers individual, societal, and institutional factors influencing sleep quality and quantity and have offered some pragmatic recommendations for enhancing sleep hygiene and promoting sleep rights. By promoting sleep stewardship, we can foster improved health outcomes and well-being for ourselves and our communities. It is my hope to stimulate further research and dialogue on this vital topic and cultivate a culture of respect and care for sleep.

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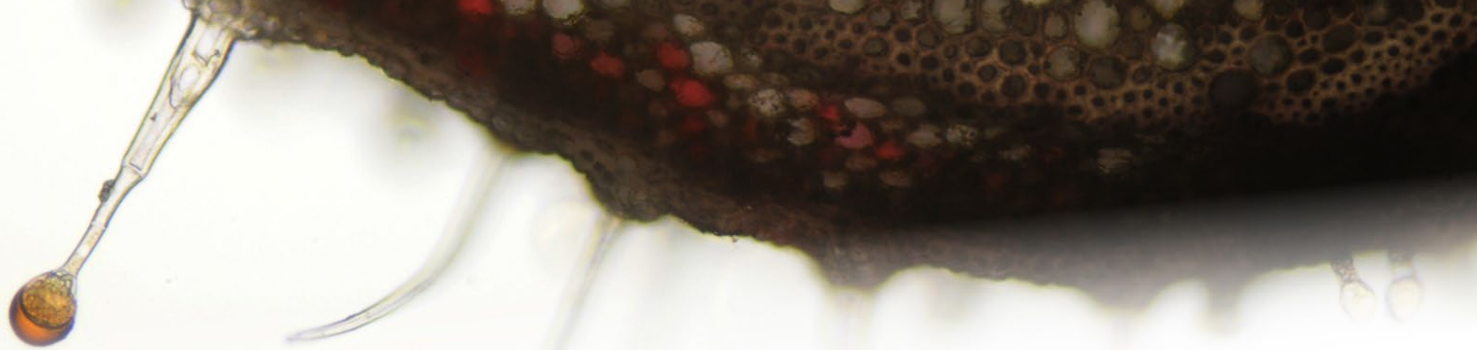
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### HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

#### Why Does the History of Circadian Rhythms Matter for Sleep Today?

Caroline Skolnik, MD and Sabra Abbott, MD, PhD

##### Abstract

A paradigm shift in circadian science is underway, exposing ethical tensions from a legacy of pervasive neglect of circadian disorders. This article canvasses ethical questions about stigma, justice, and accommodation that should be formally recognized to reconceive circadian care. Responding to these questions first requires confronting medicine's long-standing history of ableism in how circadian disorders are understood. This article also examines historical origins of the clinical and ethical need to expand diagnostic and therapeutic care access for patients with circadian disorders. Finally, this article recommends how to create space within the disabilities movement for persons with circadian disorders.

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##### What Are Circadian Rhythms?

Circadian rhythms are the near 24-hour oscillations in physiology and behavior that occur in most organisms. When functioning correctly, the circadian system responds to environmental cues, such as light and dark, and disseminates this information throughout the body—from the brain down to the level of biochemical signaling within cells. This system controls the timing of behaviors such as sleeping and eating, culminating in normative behaviors at prescribed times of day. A circadian disorder results when there is a misalignment between the body's endogenous clock and the exogenous environment.<sup>1</sup> It is both a biological and social phenomenon. Until recently, medicine has largely failed to grasp the significance of circadian rhythm pathology.

Historically, without a sufficient biological basis to characterize circadian dysfunction, the existence—let alone the severity—of circadian disorders too often went unappreciated, such that a certain level of sanctioned clinical ignorance permeated the medical community's approach to this family of disorders. Patients nevertheless continued to suffer. However, recent discoveries in the understanding of circadian science, buttressed by expanding treatment options for these disorders, have brought the field to a turning point. For example, the 2017 Nobel Prize in Medicine was awarded

to 3 researchers for identifying the molecular mechanisms underlying circadian clock regulation.<sup>2</sup>

While the circadian revolution was fomented on the research bench, it has made its way into clinical and social spheres, along with pressing ethical challenges emerging in the care of these patients. As discussed below, responding to these ethical challenges first requires confronting medicine's long-standing history of ableism and stigma, or "difference plus deviance,"<sup>3</sup> in the conception of circadian disorders.<sup>4</sup> Second, as part of the emerging need for broader access to circadian disorder care within the field of sleep medicine, challenges to expanding access to diagnostic and therapeutic care for affected patients are examined. Finally, contemporary challenges that face affected patients are explored, along with recommendations for creating a space within the disabilities movement for those impacted by circadian disorders. In short, addressing contextually relevant ethical topics—namely, stigma, justice, and accommodation—must become part of medicine's approach to reconceptualizing circadian care.

### **Circadian Disorders and Stigma**

Compared to the general population, individuals who "wake up too early in the morning" (advanced sleep-wake phase disorder) or "fall asleep later" than desired and have difficulty rising on time (delayed sleep-wake phase disorder) can be considered to have a circadian disorder.<sup>5</sup> There is substantial phenotypic variation within the family of circadian disorders, informed by differences in circadian signaling impairment. Yet disproportionate stigma is borne by the "delayed" type, often referred to as night owls, who are often mislabeled as unmotivated due to their later wake times.<sup>5</sup> Ironically, the "advanced" type, often referred to as early birds, are perceived as "good"<sup>6</sup> while their sleep disorder sequelae, such as difficulties participating in evening activities, are minimized. Additional presentations of circadian dysfunction include the non-24-hour sleep-wake rhythm disorder, characterized by erratic sleep onset timing that may be progressively delayed each day, and irregular sleep-wake rhythm disorder, comprising at least 3 separate bouts of sleep in a 24-hour day.<sup>5</sup> For all of these types, when the circadian clock fails, the ensuing circadian disorder can compromise regular sleep-wake cycles, causing disruptions in social and occupational functioning, as well as sleep disorders such as **insomnia** and hypersomnia.<sup>5</sup>

### **Overturing Stigma and Ableism**

What is standard across all types of circadian disorders is that circadian misalignment causes a physiological inability to carry out a typical human ability: to sleep "normally." Instead, sleep can occur at unusual times or become unpredictable and fragmented. Ineffectual execution of the ability to sleep normally and to participate in social and occupational functions becomes a **disability**. Within the disabilities movement, the concept of ableism describes discrimination and prejudice that ensue when expectations of typical human abilities, such as the physical ability to walk, are unmet and an individual's ability to function is perceived as "impaired."<sup>7</sup> For patients with circadian dysfunction, the experience of failure to meet expectations for sleep and of social perceptions of impairment is commonplace. People with circadian dysfunction struggle to participate in typical day and evening functions, such as attending school, work, or social events. They might be perceived as having diminished social worth due to being lower achieving, less productive members of society. Take the case of patients with delayed sleep-wake phase disorder, whose physiological inability to sleep and wake at regular times may be misconstrued as being lackadaisical, leading to social contempt and experience of incompatibility in social spheres, such as the workforce.

To complicate matters, while circadian disorder-affected patients have long been scrutinized by society through an ableist lens, the lack of scientific understanding of circadian pathology has led to 2 issues with consequences for patients: first, circadian dysfunction was woefully underacknowledged by the medical community and lacking in “true” diagnostic heft, meaning that it was not conceived of as real disorder—until the last 2 decades of the 20th century.<sup>8</sup> This lack of recognition undermined patients’ disease experience. Second, the medical community attributed the cause of circadian impairment to patients themselves. Stigma and blame surrounding circadian dysfunction were embedded in medicine’s approach to circadian disorders, with physicians depicting patient behaviors as volitional. Specifically, *behavioral* and *motivational* exemplified pejorative medical descriptions of causes or symptoms of circadian rhythm disruptions.<sup>5</sup> This rhetoric further undermined patients’ disease experience. These intertwined discriminatory beliefs—ableism and stigma—came to embody the experience of patients with circadian dysfunction, with society and the medical community reinforcing perceptions of impairment and inadequacy.

Undoing the damage that medicine has caused to the health and psyche of patients suffering from circadian disorders has begun, with science wresting causation away from patients themselves. While mapping out the scientific underpinnings of these disorders has been the first step in overcoming stigma, there are several steps in advocating for equitable access to diagnosis, disability accommodation, and nonprejudicial treatment of patients with circadian disorders. A gamut of stigma-reduction strategies targeting circadian disorders should be employed, since evidence suggests that education, training, increased contact with marginalized groups, and specific anti-stigma laws and policies are all effective.<sup>3</sup> The medical community must move away from depreciatory nomenclature. Instead, nonjudgmental neutral terminology based on pathophysiologic determinants of disease symptoms should be used, such as type 1 and type 2, to denote different phenotypes of patients affected by disordered circadian rhythms.<sup>9</sup>

### **Compromised Access to Circadian Care**

A fundamental ethical issue in circadian clinical care is diagnostic accessibility. Scientific discovery has outpaced the speed at which medical facilities have rolled out diagnostic tools. While diagnosis can largely be clinical, the availability of precision testing, such as actigraphy, pupillometry, melatonin testing, and genomic analysis, allows for tailored treatment plans. However, in most quaternary care academic sleep centers, these tests are the exception, not the rule. Moreover, even when available, testing is almost exclusively an out-of-pocket cost for patients. Actigraphy, for example, despite being recommended by the American Academy of Sleep Medicine for the diagnosis of circadian rhythm sleep-wake disorders,<sup>10</sup> is variably reimbursed by insurers, and insurers do not cover melatonin testing.

These out-of-pocket costs and limited availability create substantial inequity in the accessibility of testing. Higher socioeconomic status patients with the financial means to pay for this testing are more likely to receive a diagnosis and tailored treatment. Since actigraphy is one of the most basic tests of circadian function, lack of access to this diagnostic tool due to cost can delay or impede care. Moreover, because insurance coverage is lacking for most tools employed in the diagnosis and treatment of circadian disorders, most sleep centers do not offer these tests. As a result, the option to test is available at select specialized academic institutions to a subgroup of patients able to



pay these costs in full. For patients, lack of access to testing and care becomes an issue of distributive justice: the morally justifiable distribution of a benefit—in this case, circadian care—within a structure of social cooperation, such as a health care system.<sup>11</sup> Downstream, this lack of access may impact patients' ability to receive educational or employment accommodations, which creates a cycle of hardship for affected patients. Increasing the availability of testing, both in terms of access and insurance coverage, needs to be the focus of just clinical care in circadian treatment.

### **Seeing Circadian Disorders as Disabilities**

In the arena of circadian care, strategies to promote accommodation are crucial. In the workplace, a study evaluating the impact of aligning work shifts with circadian chronotype showed that a chronotype-adjusted shift schedule was beneficial.<sup>12</sup> This finding demonstrates that, for circadian dysfunction, accommodations are not only beneficial to patients but also obtainable. During the coronavirus pandemic, a temporary window of inadvertent accommodation appeared for patients with circadian disorders: school, work, and the bulk of social life shifted from the public sphere to online or at home, where patients could complete work or participate in social functioning in line with their own sleep and wake schedules. During the pandemic, a retreat from the rigidity of social scheduling reduced social sleep restriction, especially for people with "late" chronotypes, with improvements in "social-biological sleep timing desynchrony."<sup>13</sup> In this context, patients with circadian dysfunction thrived; having at-home or flexible work-time accommodations was significantly beneficial and an easily enacted response to circadian disability that allowed patients to participate in society in novel ways. However, as the pandemic abates, these accommodations are being rescinded, and patients with circadian disorders find themselves and their clinical care teams fighting for the right to receive them.

Ultimately, to ensure accommodations for patients with circadian disorders, they must be given a seat at the disabilities table. Receiving a place within the growing disabilities movement would achieve several things. It would reshape the experience of impairment, bringing circadian disorders into the arena of medical diseases requiring accommodations, which ultimately would chip away at stigma. On a structural level, empowering patients would change the culture of institutions that have traditionally failed to accommodate circadian disability by combatting long-standing ableism, thereby forwarding the argument that people with disabilities live with functioning that differs from that of those without disabilities but that ought not be the basis for deviance and inferiority.<sup>7</sup> From a pragmatic standpoint, creating disability policy for circadian dysfunction means confronting structural barriers. For example, because the objective levels of "impairment" required by Social Security disability benefits may not be met by those with an **invisible disability**, such as circadian dysfunction, laws, policies, and other social structures that perpetuate denial of disability recognition and accommodation will need to be challenged. Expanding the notion of invisible disability as it pertains to circadian disorders will need to become a centerpiece of advocacy for disability accommodations for circadian dysfunction.

### **Present and Future**

Much work remains to be done in the way of ethical delivery of care for patients with circadian disorders to right the medical community's historical wrongs of stigma and ableism and to bolster social policies that promote inclusion and empowerment. Discoveries in circadian science have paved the way for pathophysiological distinctions that medicine has recognized as quantifiable and veritable disorders. However, the

secondary impacts of this paradigm shift have created inequities in access to care and called attention to the need for disability rights for those afflicted by circadian disorders.

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