



AMA Journal of Ethics®

October 2024, Volume 26, Number 10: E816-821

HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

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

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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.¹ 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.²

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,"³ in the conception of circadian disorders.⁴ 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.⁵ 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.⁵ Ironically, the "advanced" type, often referred to as early birds, are perceived as "good"⁶ 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.⁵ 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.⁵

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."⁷ 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.⁸ 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.⁵ 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.³ 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.⁹

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,¹⁰ 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.¹¹ 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.¹² 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.”¹³ 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.⁷ 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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Citation

AMA J Ethics. 2024;26(10):E816-821.

DOI

10.1001/amajethics.2024.816.

Conflict of Interest Disclosure

Authors disclosed no conflicts of interest.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.