Ethics Commentary

DISORDERS OF SLEEP

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Ethical Considerations in Sleep Medicine

Abstract: As we adopt a forward-looking perspective in the still emerging field of sleep medicine, it is imperative to revisit a set of core ethical principles to serve as a road map in this journey. The foundational concepts of nonmaleficence, autonomy, truthfulness, justice, and beneficence must inform our efforts and guide our actions as we set about to conduct this important work. The primary responsibility of a medical provider is to act in a way that does not cause additional harm to a patient beyond the inherent and unavoidable consequences of a disease process. To avoid potential adverse effects, the judicious use of prescription medications, including sleeping pills, is imperative. Patient autonomy and veracity must be preserved by disclosing the association between REM behavior disorder (RBD) and other neurodegenerative conditions. Distributive justice requires access to basic medical care and fair allocation of resources, including an equal share of public safety, to all members of society. Through education, access to diagnostic procedures, and timely therapy, significant impacts can be made throughout public health. The opportunity for great beneficence exists in the discipline of sleep medicine with a substantial need and effective treatments strengthened by the integral role of technology. Medical care that is founded on these basic ethical standards will ensure continued success as the specialty continues to develop.

> "Weary with toil, I haste me to my bed
> The dear repose for limbs with travel tired;
> But then begins a journey in my head
> To work my mind, when body's work's expir'd"
> –Sonnet 27, Shakespeare (1)

Though the physiology of sleep has not ostensibly changed for millennia, our expectations of it have. The contemporary perception of sleep as an inconvenience, lost time for productivity and leisure, has begun to slowly transition as we increasingly recognize its vital role in countless aspects of health. Concurrently, the perpetual emergence of novel treatments, medications, and technological advancements provide opportunities to enhance, and perhaps corrupt, this most basic of functions. As we adopt a forward-looking perspective in the still emerging field of sleep medicine, it is imperative to revisit a set of core ethical principles to serve as a road map in this journey. The foundational concepts of nonmaleficence, autonomy, truthfulness, justice, and beneficence must inform our efforts and guide our actions as we set about to conduct this important work.

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Introduction to Ethical Principles

Medical ethics relies on a set of core moral principles and values that guide practitioners in a clinical setting to act in the best interests of their patients. This framework depends on four cardinal cornerstones (2):

1. Nonmaleficence (*primum non nocere*: "first, do no harm");
2. Autonomy (deliberated self-rule, most importantly, the right to consent to or refuse treatment);
3. Justice (fairness, equality, and the distribution of scarce health resources); and
4. Beneficence (responsibility to act in the patient's best interests to maximize positive consequences).

In addition, preservation of the dignity of all human beings and the adherence to veracity (or truthfulness) are also posited as key features of an ethics-centered practice (3). The application of these ideals to sleep medicine requires careful reflection, but they can prove invaluable in routine clinical decision-making to best serve patients.

First, do no harm

The primary responsibility of a medical provider is to act in a way that does not cause additional harm to a patient beyond the inherent and unavoidable consequences of a disease process. In the realm of sleep medicine, harm may manifest in multiple ways, especially as a consequence of the potent pharmaceutical agents that are commonly employed in practice. These highly controlled substances may include sleeping pills, stimulants, narcotics, and even sodium oxybate (used illegally as the "date rape drug"). Due to their expansive use, sleeping pills deserve special attention.

Insomnia is the most commonly encountered sleep condition in a primary care setting, so it is little surprise that sedative and hypnotic medications would be widely prescribed to address this ailment (4). In a recent report of the use of prescription sleep aids by the Centers for Disease Control and Prevention, it was estimated that between 2005 and 2010 about 4% of U.S. adults aged 20 and older used sleeping pills in the previous month (5). According to IMS Health, an agency which tracks drug data, about 59 million sleeping pills were prescribed in the United States in 2012, up from 56 million in 2008 (6). In a more troubling statistic, market research has revealed a tripling in sleep aid prescriptions from 1998 to 2006 for young adults aged 18–24 (7). Formerly employed sleep-inducing medications such as barbiturates raised ethical concerns in the 1970s (8). Though newer nonbenzodiazepine medications such as zolpidem, eszopiclone, and zaleplon have a shorter track record, there may be some emerging evidence of possible adverse effects associated with their use as well.

In a widely discussed British Medical Journal study from 2012, it was found that people who took sleeping pills were nearly five times as likely to die over 2 1/2 years as those who did not. In addition, though admittedly small, an association was noted between heavy use and a higher incidence of cancer (9). Previous large studies also support the correlation between sleeping pill use and increased mortality (10–13). Critics point out that these studies have numerous confounding variables and do not prove causation, but when considering the importance of maleficence, these data should at least provoke some reflection and prompt additional study.

Though further long-term study of sleeping pills is necessary to assess potential consequences, even the immediate effects may give a prescribing provider pause (14, 15). These risks should be taken into account and fully disclosed to patients. In many cases, cognitive behavioral therapy for insomnia (CBTI) may be an effective and appropriate alternative to the use of sleeping pills.

Additional therapies within sleep medicine also require proper discernment to prevent patient harm. Other pharmacological treatments, including the use of stimulants, carry a potential for overuse and even abuse. Sodium oxybate, which is highly effective in treating narcolepsy with cataplexy, carries its own potential risks, and thus its distribution is tightly regulated. In some cases, narcotic medications (including methadone) are indicated for the treatment of intractable restless legs syndrome. These medications can be highly effective in the proper clinical setting, but they should be administered by providers who have the clinical expertise to ensure appropriate use. The role of sleep specialists in this process is readily apparent, but, as discussed below, the growing scarcity of this resource may present its own set of problems.

Autonomy and truthfulness

To understand the importance of respecting patient autonomy and adhering strictly to the ideal of truthfulness in the context of sleep medicine, it is helpful to consider the example of the diagnosis of REM sleep behavior disorder (RBD) and the associated development of other neurodegenerative conditions. For reference, there was a wonderful discussion of this ethical issue in the American Academy of Neurology's February 2013 edition of *Continuum* (16). Importantly, within a decade more than 50% of people with RBD will go on to develop another synucleinopathy, such as Parkinson's disease, dementia with Lewy bodies, or multiple systems atrophy (17–19). The longer these individuals are followed, the higher the incidence of these comorbid neurological conditions occurring (17). Because the onset of RBD may precede these other conditions by many years, even decades, the disclosure of the diagnosis has important implications.

In order to respect the autonomy of the patients, once the diagnosis is appropriately confirmed, it is necessary to fully disclose the likelihood of long-term

neurological complications. Though there may be some uncertainty in the precise clinical course, this knowledge can serve as an impetus to sustained medical follow-up with appropriately timed intervention. Moreover, with this information in hand, these patients can then make appropriate medicolegal arrangements and accommodations to ensure sustained quality of life, including addressing any incipient mobility and cognitive impairments. Withholding this knowledge would additionally violate the ethical standard of veracity.

PRINCIPLE OF DISTRIBUTIVE JUSTICE

Within medical ethics, another central tenet that may get less attention is the concept of distributive justice (20). Relying heavily on ideals of fairness and equality, this standard recommends that everyone have access to basic medical care and to the fair allocation of resources. As a corollary to this, all members of society are entitled to an equal share of public safety. When considering the implications within the context of sleep medicine, access to specialists and testing, as well as the public health implications of poor sleep become of paramount importance.

Like many disciplines within medicine, sleep specialists face increasing pressure to deliver services to a greater number at a reduced cost. As the millions of uninsured Americans gain access to healthcare through the Patient Protection and Affordable Care Act, this will only be exacerbated. Meanwhile, insurers have been reducing reimbursement for in-center diagnostic testing, which has traditionally been an important revenue stream to these providers. The resulting financial uncertainty may be discouraging new trainees from entering the field. In the most recent sleep medicine fellowship match, there were 64 programs offering 129 positions to start in July 2013. Much to the alarm of leaders in the field, 31 positions (or nearly 25%) went unfilled, including spots at the nation's most prestigious programs (21). As medical professionals shy away from the practice of sleep medicine, there is likely to be an increased shortage to meet the impending needs.

In order to properly meet the medical needs of patients with sleep disorders, there may be more reliance on primary care providers, midlevel providers, and allied health professionals. Access may be extended through tele-health and online resources. Additionally, diagnosis of obstructive sleep apnea and even therapeutic titration of continuous positive airway pressure (CPAP) devices may become more dependent on systems able to perform monitoring at home. It will be imperative to ensure highquality standards, both in regard to the education of these allied professionals as well as in the utility of out-of-center testing. In most cases, as much as possible, medical care should still be directed by a sleep specialist, especially when more complicated conditions or treatments are involved. With a growing scarcity of these resources, how they can be made accessible will require both intelligence and fairness.

Sleep problems are inextricably linked to public health concerns and in order to provide equal shares of public safety, education and treatments must be extended to all members of society. Major disasters from the Exxon Valdez oil spill to the Chernobyl nuclear meltdown have, at least in part, been attributed to sequelae from sleep deprivation. It likewise contributes to countless automobile, bus, train, and plane accidents. Drowsy driving and falling asleep behind the wheel may cause upward of 20% of vehicular accidents (22). As a result, restrictions have been placed on professions within the transportation industry. Sleep specialists must carefully assess the risk of drowsy driving and accidents with prompt intervention, though the specific laws related to reporting and driving restrictions vary by state (23). In another manifestation of these effects, the adverse consequences associated with sleep deprivation among medical residents have prompted duty hour restrictions to reduce medical errors at teaching hospitals (24). Throughout the economy, the losses in productivity due to impaired performance, errors, and other consequences of sleep disorders are certainly extraordinary. The chance to intervene is an opportunity that cannot be missed.

POTENTIAL FOR BENEFICENCE

For practitioners within sleep medicine, one of the greatest appeals of the work is the potential to do great and lasting good in the lives of patients. The various sleep disorders are exceedingly common and the possibility for effective treatments exists for many conditions. Interventions can be immediately life-saving, but may more often exert their impact by reducing the long-term risk of significant health consequences. The emergence of new technologies increases the opportunities to make lasting and beneficial impacts among those afflicted.

Sleep disorders are extremely common.

Fortunately, effective treatment options exist to remedy or improve the symptoms associated with many of the sleep disorders. The potential for these various treatments to significantly alleviate the underlying sleep disorder and improve the corresponding daytime function is heartening.

An important role of the treating physician in sleep medicine is to implement treatments to mitigate the risk of harmful consequences. The interplay between

comorbid insomnia and psychiatric disorders like anxiety and depression is well known; the increased risk of suicide among this population requires action (25, 26). It is necessary to recognize the coincidence of these conditions with careful inquiry and treat them concomitantly. The societal costs associated with these medical complications are astounding, and treatment can eliminate an important risk factor for these long-term adverse consequences. Other interventions can have more immediate effects. In particular, taking appropriate safety precautions among those with parasomnias such as sleepwalking or RBD can prevent injuries, falls, and even death (27, 28). In the latter condition especially, these protections may also eliminate inadvertent harm to a bed partner.

A final component to the discipline of sleep medicine continues to evolve: technology. From its inception, and especially in the last 50 years, the field has changed in remarkable ways due to its influence. This evolution continues, with the emergence of new technologies that aid in the diagnosis and effective treatment of sleep disorders. There is no reason to suspect that this advancement will abate. Online resources give patients unfettered access to knowledge about their medical conditions. This information can be useful, if of reputable source and interpreted by a discerning mind, especially with the assistance of a medical professional skilled in its proper clinical application. The sustained utility of this technology serves as a major strength of the specialty.

Conclusions

The future of sleep medicine is bright. With continuing technological and scientific advancements, novel pharmaceutical treatments, and an increasing awareness of the importance of sleep, the opportunities to benefit patients grow. The need is great, as is the responsibility of providers to ensure that quality care is delivered efficiently with attention toward ensuring optimal patient outcomes. By providing medical care founded on these basic ethical standards, success will be ensured and the satisfaction that is so integral to sleep medicine can be attained.

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