

Ethics of sleep, clinical practice and the law



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Our cultural ideas about sleep and its relationship to our physiological needs, health and safety are changing rapidly

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Introduction

Ethical behaviour is core to the practice of sleep medicine. Sleep medicine raises questions in three often distinguished subcategories of ethics - normative ethics (how should we behave?), metaethics (when ethical principles conflict, how do we decide which takes precedence?) and applied ethics (what conduct is proper for certain groups of people or under certain circumstances?). Beyond the normative ethics of everyday clinical decision-making, physicians also confront conflicting ethical standards when practising evidence-based sleep medicine and how to apply clinical ethics to new discoveries in neuroscience that influence the practice of sleep medicine. It is incumbent on sleep practitioners to be self-aware when it comes to potential influences on their decision-making and to adjust their behaviour accordingly. As sleep medicine transitions to a chronic care/disease management specialty with an emphasis on patient-centred care, it will be especially important to have a clear set of patient-centred values.^{1,2}

Our cultural ideas about sleep and its relationship to our physiological needs, health and safety are changing rapidly. Sleep deficiency, defined as insufficient quantity or quality of sleep for optimal health and performance, can arise from inadequate total sleep duration or from fragmentation of sleep.

LEARNING OBJECTIVES

You will learn:

- The association between sleep deficiency and poor health and safety outcomes
- Common ethical considerations in the clinical management of sleep-related disorders
- Civil and criminal law considerations in respect of culpability for acts ascribed to sleep-related violence or excessive daytime sleepiness.



Shorter sleep duration of six or fewer hours per night is associated with negative health outcomes including obesity, hypertension, glucose intolerance, diabetes, chronic gastroenteritis/peptic ulcer, chronic obstructive pulmonary disease, cardiovascular disease, ischaemic heart disease and death. Poor mental health is also an effect; depressive symptoms are associated with shorter sleep duration, which itself increases the risk for the development of depression.^{3,4}

In a national study of persons 50 years and older in South Africa, the prevalence of short sleep was 11.4%. The sociodemographic factors of older age, female sex and greater wealth status, along with the lifestyle factors of inadequate fruit intake, current tobacco use and physical inactivity, have been found to be associated with short sleep duration. Individuals may be unaware of their degree of impairment

consequent on sleep deficiency.^{3,4}

Sleep disorders and sleep deprivation can often lead to situations with legal and regulatory ramifications related to driving, employment, surgical procedures, underdiagnosis or misdiagnosis of obstructive sleep apnoea (OSA), and parasomnia-associated sleep-related violence, among others. Clinicians must be aware of these issues and screen, treat and educate their patients.

In the context of a sleep-related disorder, what is legal and what is ethical are not always the same; the law is less concerned with the specific condition than with the ‘blameworthiness’ of the perpetrator in respect of the act leading to the negative outcome, which is addressed by the legal issue of culpability. The approach to the concept of culpability differs in civil and criminal law (Box 1).

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Box 1. Culpability – civil and criminal law

Civil actions

In South Africa, the circumstances in which one person can claim compensation from another for harm that has been suffered usually fall under the law of delict, the elements of which are:

- Harm sustained by the plaintiff
- Wrongful conduct on the part of the defendant
- A causal connection between the conduct and the plaintiff’s harm
- Fault or blameworthiness on the part of the defendant.

Criminal law

In Roman Dutch law, there can be no punishment without culpability - *Could one in all fairness have expected the accused to avoid the wrongdoing?*

Intention, an inquiry into the subjective state of mind of an accused at the time of the offence, extends to:

- What a person may have as his/her purpose (*dolus directus*)
- What is foreseen as inevitable (*dolus indirectus*)
- What is foreseen as a real possibility (*dolus eventualis*)

Proof of intention is complex because it is concerned with the internal subjective state of mind of an accused. The motivation underlying the intention may render an otherwise unlawful act lawful, and therefore not punishable.

Excessive daytime sleepiness

Excessive daytime sleepiness can be due to OSA, narcolepsy, restless leg syndrome, insomnia, insufficient sleep syndrome, medication-induced sleepiness and other medical disorders.

Everyday ethical questions that may commonly arise centre on diagnosis, ensuring the patient is aware of their treatment options, including no treatment, and that they understand the advantages and disadvantages of each option. There are many reasons why an in-laboratory study might be a preferred diagnostic pathway

for a given patient, but personal financial gain or cost-savings alone should never supersede best-practice decision-making.

Because positive airway pressure (PAP) is the most efficacious treatment for OSA, most sleep clinicians view it as the default treatment of choice for all patients. Ethical behaviour demands that providers inform patients of their treatment choices, and patients who actively choose their treatments experience improved adherence and health-related outcomes. The irony is that most patients will choose a trial of

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PAP for their OSA when presented with a balanced summary of the evidence.

Too often, when treating insomnia, sleep medicine providers rush to pharmacotherapy without understanding the cause of a patient's sleep complaints: Do

you discuss the risks and benefits of prescription sleep aids? Do you administer behavioural strategies or refer for formal cognitive behavioural therapy (CBT)? At a minimum, do you require insomnia patients to complete sleep diaries?¹

The dangers of daytime sleepiness

Lack of sleep has an objective impact on functioning. A healthy person who stays awake for 18 hours has a deficit in reaction time equivalent to that of a person with an alcohol level that would define that person as impaired.⁵

Insufficient sleep syndrome, or chronic voluntary sleep restriction, resulting in excessive daytime sleepiness and daytime fatigue is particularly important in those working in safety-sensitive occupations such as commercial trucking, aviation, railroads and construction.⁶ Being sleepy while on duty can cause many occupational accidents and injuries. Fatigue caused by sleep loss is also a risk to physician and patient safety. Extended overnight shifts increase the likelihood of chronic sleep restriction in interns and registrars, with significantly reduced levels of alertness in the morning after on-call nights.⁷ Inadequate rest, sleep pattern disturbances and more frequent overtime shifts are associated with healthcare worker burnout. South African healthcare workers have a higher prevalence of

burnout and stress-related mental disorders than the general population and report higher rates of burnout than their international peers.^{8,9}

Daytime sleepiness, headaches and cognitive deficits, such as reduced ability to concentrate, are common in patients with OSA, which has a prevalence of approximately 5% in adults. A recent meta-analysis concluded that patients with OSA have a crash risk approximately 2.5-fold that of individuals without sleep apnoea. Of serious motor vehicle crash injuries, 20% are attributable to sleep disorders and sleep deprivation. Of fatal crash injuries, estimates are that 21% are attributable to drowsy driving (Box 2).³ Because OSA is a significant independent causative factor of road traffic accidents, should OSA patients be allowed to hold a valid driving licence before their illness is satisfactorily treated? Diagnosis of OSA should consider the degree of sleepiness that can lead to functional impairment, as sleepiness is not the exclusive contributor to impaired cognitive or executive functions.

Box 2. The law and sleepy drivers

The 'sudden blackout' defence is a legal protection for drivers who suffer from a sudden and unforeseen onset of sleep, but this may be difficult to establish if the patient has a prior history of a tendency to fall asleep while driving.

Patients with sleep disorders must be informed of the risks of participating in safety-sensitive occupations while drowsy and of the risks of driving, that there may be civil and/or criminal liability if they fall asleep or have cataplexy while driving. Discussion should be documented appropriately in the medical history.

Although physicians must attempt to identify risks from excessive sleepiness and reduce the possibility that patients will harm themselves or others in any way, they cannot be held legally responsible for information that is not readily apparent on a clinical examination or that is not disclosed by the patient.

Diagnosis of OSA should consider the degree of sleepiness that can lead to functional impairment

Parasomnias

Parasomnias are undesirable experiences that may occur during either rapid-eye-movement (REM) or non-REM (NREM) sleep.

A patient with REM behaviour sleep disorder (RBD) may act out their dreams, placing themselves or bed partners at risk. Furthermore, the RBD patient has

as much as a 65% risk of developing an α -synucleinopathy, including Parkinson's disease, dementia with Lewy bodies and multiple system atrophy; RBD can also be seen in spinocerebellar ataxia type 3, Huntington disease and other neurological conditions. Currently, it is not possible to predict whether an individual will

develop a disease or, if so, which disease. The clinician treating the patient must consider the difference between disclosing a diagnosis and disclosing the risk of

a diagnosis; whether to disclose this risk to patients; and, if deciding to disclose the risk, the appropriate timing of such a conversation (Clinical case 1).¹⁰

Clinical case 1. Weighing the duty to inform a patient of possible future illness¹¹

Mr du Toit, 58 years old, has a history of violent behaviour during sleep, with episodes of shouting, kicking and punching that his wife finds extremely frightening. After conducting a thorough history and physical examination, Mr du Toit is diagnosed with idiopathic RBD. His clinician knows that Mr du Toit, although currently healthy, has a significant chance of developing a neurodegenerative disease within the next 10-15 years. The clinician must now decide whether to inform Mr du Toit of this risk, given that there is a chance he may not develop neurodegenerative disease and may experience depression and grief if informed of this possibility, thereby affecting his current quality of life. Furthermore, there is currently little to be done to prevent or delay the onset of disease.

The clinician may harm Mr du Toit to some degree either by informing him of the risk or by withholding the knowledge of future disease; and must weigh the duty to avoid unnecessary psychological burden against the duty to be truthful and forthcoming with important information that may affect his future.

The clinician has a duty to make relevant information available to his patient

By informing Mr du Toit, the ethical principles of beneficence and autonomy are fulfilled. This knowledge may be important for planning and making decisions about relationships, retirement, finances and travel. Furthermore, Mr du Toit might benefit from future discoveries and new interventions that become available before his disease's onset.

The clinician must balance the duty to inform his patient with the principle of nonmaleficence

Is the psychological burden of knowing that he is at increased risk for a neurodegenerative disease justifiable? Is there a reasonable clinical suspicion that such knowledge may prompt the development of depression, or exacerbate other conditions such as anxiety? Even if he is diagnosed in the future, the time until onset may be so long as to minimise the beneficial value of being informed now.

... consider the difference between disclosing a diagnosis and disclosing the risk of a diagnosis

Most parasomnia-associated sleep-related violence (SRV) is directed toward oneself, but it presents a potential medico-legal issue as a possible contributing, mitigating or exculpatory factor in criminal proceedings. SRV directed at others, such as assault, homicide, sexual assault/rape or motor vehicle-related offences, are the incidents that come to the attention of the criminal justice system (Clinical case 2). The prevalence of SRV is unknown and may be underestimated.

A spectrum of NREM disturbances of arousal range from confusion to sleep terrors and includes sleepwalking with or without the performance of complex behaviours. Reports of sexual behaviour during sleep (SBS) have recently been published, including attempts by patients to have intercourse with their partner or even objects, often with a certain degree of aggression and violence, obscene language or even masturbatory activity. This behaviour is generally quite at odds with the patient's habitual wakeful characteristics.

Seizures causing nocturnal violence normally originate from a frontal focus,

causing disinhibition and violent thrashing motions. Temporal seizures have also rarely been noted as a cause of sleepwalking and night-time violence. The violence can occur during the prodromic phase, the seizure itself or in the postictal period. Because of the non-standard presentation of these seizures, they can often be indistinguishable from other sleep disorders.

Psychogenic nocturnal dissociative states are recognised as occurring in the awakened state, often leading to unexplained behaviour such as travelling a long distance, and are associated with amnesia and violence. Such states could occur with the patient seemingly asleep on behavioural observation for the entire episode, even though they have sustained EEG wakefulness.

Medication-associated parasomnia, a potential adverse effect of benzodiazepines and non-benzodiazepine benzodiazepine receptor agonists, has been associated with sleepwalking and other complex behaviours. Zolpidem is the best studied agent; the clinical features of zolpidem-associated complex behaviours include poor motor control, dysarthria

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and ataxia. Responsiveness to the environment manifests as apparent wakefulness to observers, confused ideation and irrational speech, and anterograde amnesia.

Malingering is the deliberate and false

representation or the faking of a symptom (or suggestive parasomnia state) for personal benefit, frequently criminal. Defence against charges of homicidal intent would be an appropriate example.

Clinical case 2. Giving medical testimony on a patient's behalf¹²

Dr Carter is fond of Mr Conrad, 23 years old, and knows his family well. Dr Carter is shocked to find out that Mr Conrad, a patient since childhood, has been arrested and charged with attempted murder after throwing his baby out of the window of his flat. When the police arrived, Mr Conrad was found standing outside the building in his pyjamas and was arrested; he has no recollection of the events and claims the police woke him up when they arrived on the scene.

Dr Carter remembers the many accidents Mr Conrad has had when sleepwalking over the years. Despite a thorough neurological work-up, he never found any pathology that could cause the sleepwalking and thought Mr Conrad would eventually outgrow it. Because Dr Carter can't imagine something as benign as sleepwalking resulting in attempted manslaughter, he is hesitant to help in the defence of this case. Furthermore, Dr Carter feels that this is not part of his duty as a physician.

Serving the court in a professional clinical capacity

Generally, clinicians testify either as medical experts or as individuals with the most intimate knowledge of a defendant's medical history. As a family physician who has no specialty training in sleep disorders, it is unlikely that Dr Carter qualifies as an expert medical witness, but he can provide limited relevant information to the court. If requested to testify, Dr Carter should carefully consider his obligation in the administration of justice, Mr Conrad's medical interests, and his ability to provide testimony that reflects current scientific thought and standards of medical practice.

The patient-doctor relationship in court

If called upon to testify, Dr Carter is legally compelled to disclose Mr Conrad's medical history in an objective and independent manner. He may also be expected to provide information about Mr Conrad's character, even if disclosing such information could damage Mr Conrad's defence. Dr Carter must make every attempt to give testimony that is fact based and as objective as possible.

... motor function may be separate from cognitive awareness, which is a prerequisite for criminal responsibility

The law and sleep-related violence

Legally, if an individual is neither awake nor able to make a decision not to act, such actions are termed automatism, of which there are two categories - sane automatism and insane automatism. Sane automatism results from an external factor, for example, a blow to the head. Insane automatism results from an internal factor, for example, a brain tumour or a psychological factor. Given that parasomnia is probably a neurological disturbance, it falls into the category of insane automatism, and unfortunately may lead

to institutionalisation of those who are not mentally ill. The current understanding of neurology, and of parasomnias in particular, has shown that motor function may be separate from cognitive awareness, which is a prerequisite for criminal responsibility.

The most consistent risk factor for SRV is male gender. This finding is concerning, given the obvious incentive of men who commit violence against women to malingering, seeking parasomnia-related automatism as a legal defence.

The role of the sleep medicine physician in parasomnia legal cases

In most SRV cases, sleepwalking is the purported defence. Consensus guidelines for the evaluation of SRV and/or SBS cases are lacking. Recommendations for clinical work-up include a complete history and physical, with special attention to historical details of habitual sleep-wake periods, prescribed medications (particularly hypnotics), illicit drug use,

alcohol use, a personal history of prior parasomnia behaviours, and a family history of parasomnia behaviour.

Recollection of vivid, frightening dream imagery may suggest either sleep terrors or REM-associated nightmares. Electrophysiological evaluation in SRV or SBS cases should include video polysomnography with surface electromyography

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assessment of all four limbs. A protocol using sleep deprivation combined with auditory stimuli has been shown to be effective in inducing parasomnia behaviour in the sleep laboratory setting.

Sleepwalkers don't generally seek out the eventual victim. More often, a person attempting to restrain, redirect or

awaken the sleepwalker during an episode is attacked unintentionally with primitive defensive aggression in the form of punching and kicking. Ultimately, conviction or acquittal is based on the forensic evidence at the scene of the incident and, if available, eyewitness testimony.

KEY LEARNINGS

- Sleep medicine raises questions in the categories of normative ethics, metaethics and applied ethics
- Civil and criminal law view culpability differently
- Excessive daytime sleepiness is associated with an increased risk of occupational and motor vehicle accidents
- Parasomnias are undesirable experiences that may occur during either REM or NREM sleep
- RBD is associated with an increased risk of developing an α -synucleinopathy
- Parasomnias are associated with SRV, SBS and amnesia
- Sleepwalking and other complex behaviours have been observed in medication-associated parasomnia.

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