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# (Mis)Perceiving Apnea and Insomnia in Germany: A Tale of Two Disorders

Julia Vorhölter 

Department 'Anthropology of Politics and Governance', Max Planck Institute for Social Anthropology, Halle (Saale), Germany

## ABSTRACT

In Germany, both apnea and insomnia are highly prevalent sleep disorders. But while there is an extensive and growing infrastructure to deal with apnea, there is very little support for insomnia patients. I argue that this is due to various interrelated factors: the role of evidence and experience in diagnosis, the availability of treatment, and—importantly—how evidence, experience, and treatment can (or cannot) be materialized in the medical economy. Drawing on phenomenology and affordance theory, and based on fieldwork among German sleep doctors and their patients, I analyze how different sleep disorders are perceived, evaluated, and acted upon. I use different examples to reflect on the possibilities of “objectively” knowing and “subjectively” experiencing (disordered) sleep, and on how different perspectives (patient versus doctor, first-person versus third-person) and modes of perception (direct or indirect, narrative-based anamnesis or technology-based assessment) matter (or not) for the diagnosis and treatment of sleep disorders.

## ABSTRAKT

In Deutschland haben sowohl Insomnie als auch Schlafapnoe eine hohe Prävalenz. Während es jedoch eine wachsende medizinische Infrastruktur für die Behandlung von Apnoe gibt, haben es Insomnie-Patient\*innen schwer, Hilfe zu finden. Ich argumentiere, dass dies an verschiedenen, miteinander verwobenen Faktoren liegt: die Rolle von Evidenz und Erfahrung bei der Diagnose, die Verfügbarkeit von Behandlungsmöglichkeiten, und – am wichtigsten – wie profitabel verschiedene Formen von Evidenz, Erfahrung und Behandlung in der medizinischen Ökonomie sind. Mit Rückgriff auf phänomenologische Ansätze und die Affordanz-Theorie, und basierend auf Feldforschung mit Schlafmediziner\*innen und ihren Patient\*innen in Deutschland, analysiere ich, wie Schlafstörungen wahrgenommen, evaluiert, und behandelt werden.

## KEYWORDS

Affordance theory; evidence; Germany; medical economy; phenomenology; sleep medicine

At an afterwork party I was talking to my colleague Pia.<sup>1</sup> She knew about my research on sleep and was telling me how her father had recently spent two nights in a sleep lab where he was diagnosed with mild apnea.<sup>2</sup> Soon other colleagues joined our conversation and, as I have often experienced in such settings, everyone had a story about sleep. Most of the guests worked on fixed-term contracts in high-paced academic jobs, and few of them slept well. Tales quickly shifted: from reports about parents who suffered from apnea to personal narratives about

**CONTACT** Julia Vorhölter  [vorhoelter@eth.mpg.de](mailto:vorhoelter@eth.mpg.de)  Department 'Anthropology of Politics and Governance', Max Planck Institute for Social Anthropology, Advokatenweg 36, 06114 Halle (Saale), Germany

**Media Teaser:** Why does German sleep medicine give so much attention to apnea and so little to insomnia, even though both disorders have a similarly high prevalence.

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insomnia. People exchanged stories of lying awake at night with their mind racing around upcoming deadlines, ending contracts, or new research ideas. Others described how they collapsed into bed dead-tired at night only to wake up at 3.30 am when, with no hope for further sleep, they started work. I listened, with the open ears of a fieldworker and with the empathetic concern of someone who had experienced the horrors of insomnia. After a while, I rejoined Pia, who was still talking about her father and how, ever since his apnea diagnosis, he had developed a fear of dying in his sleep. Trying to reassure her, I said that his apnea score seemed comparatively low and nothing to get too worried about. I told her about the much-heralded “apnea epidemic” that I was constantly encountering in my fieldwork and the markets and interest groups that seemed to be forming around it, including sleep labs, self-help groups, and mask companies. Everything in the world of sleep medicine seemed to revolve around apnea. And while a few years ago people like Pia’s dad, whose main symptom was bad snoring, would probably have never been screened for apnea in the first place, nowadays waiting lists for sleep lab in some places were over two years. We kept talking, about the reasons for this “epidemic,” about new therapeutic interventions, and about the dangers of untreated severe apnea. Another colleague, herself a bad sleeper, who had been listening to our conversation suddenly interjected: “Apnea seems so boring! Why is there so much focus on apnea and so little on insomnia?”

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This article takes my colleague’s question as a starting point: Why does German sleep medicine give so much attention to apnea and so little to insomnia? The answer, I argue, may be found in various interrelated aspects: the role of evidence and experience in diagnosis, the availability of treatment, and – importantly – how evidence, experience, and treatment can (or cannot) be materialized in the medical economy. I will show that apnea, which at first glance might seem boring to the anthropologist, is of huge interest for doctors, medical tech producers, and insurance companies: because diagnosis is based, quite literally, on “sound evidence”<sup>3</sup>; because successful treatment is widely available; and because both diagnosis and treatment offer good opportunities for making money. Insomnia, by contrast, is a nightmare (so to speak) for doctors – for all the reasons that make it (potentially) interesting for the anthropologist or the numerous novelists and poets who have written about it (see Johnson 1990). Insomnia is a profoundly subjective illness which is hard to measure “objectively.” To both diagnose and treat insomnia, doctors must engage with patients’ experiences. This may involve listening to rich, often long, accounts of personal struggles and suffering – a time-consuming practice that does not pay well. But while anthropologists, novelists, and poets are attracted to complex stories, doctors seek unambiguous evidence which, like the polysomnography,<sup>4</sup> ideally comes in the form of numbers, scores, and graphs.

In this article I have two main objectives: on a practical level, to understand why, despite insomnia’s high prevalence, treatment options in Germany are so scarce. On a more theoretical level, I reflect on the possibilities of “objectively” knowing and “subjectively” experiencing (disordered) sleep, and on how different perspectives (patient versus doctor, first-person versus third-person) and modes of perception (direct or indirect, narrative-based anamnesis or technology-based assessment) matter (or not) for the evaluation and treatment of sleep disorders. Drawing on phenomenology and affordance theory, I argue that apnea and insomnia have different affordances for doctors based on how they can or cannot be perceived and acted upon. These affordances affect how apnea and insomnia are positioned in the medical economy, which helps to explain why ever more people are diagnosed with and treated for apnea while insomniacs struggle to be taken seriously and find help.

My findings are based on ongoing research I have been conducting on German sleep medicine since late 2021. I carried out participant observation in a sleep lab, which involved observing diagnostic procedures, therapeutic interventions, and doctor-patient interactions. I interviewed patients suffering from insomnia as well as doctors and other experts who deal with sleep disorders, apnea and insomnia, in particular. And I attended the annual conferences of the German Society for Sleep Medicine and Sleep Research (DGSM) in 2021 and 2022.

In Germany, sleep medicine is a very small and relatively recent field (the professional association DGSM was only founded in 1992). There is no designated specialist or *Facharzt* for sleep medicine which poses far-reaching problems for the treatment of sleep disorders. For instance, medical students are rarely specifically trained in sleep medicine, patients do not know where to go with their sleep problems, and general practitioners sometimes do not know if and where to refer them. Doctors can obtain the additional qualification (*Zusatzqualifikation*) “sleep doctor” which allows them to bill for assessments like the polysomnography. Due to its heavy focus on apnea, obtaining this qualification makes sense for pneumologists (who dominate the field) or ear-nose-and-throat specialists, but less so for other specialists (like psychiatrists, for instance).

As is true for most labs in Germany, the sleep lab I studied is run by a pneumologist (with the extra qualification “sleep doctor”) and is primarily equipped to deal with sleep apnea, although patients with other sleep disorders are sometimes admitted too. Patients usually come for three consecutive nights: one night for diagnosis (the prime focus being on apnea-related events) and two nights for therapy, during which airway-pressure masks are tested and adjusted.<sup>5</sup> I was able to engage with patients and staff during the evening, night and early-morning shifts and to sit in on the consultations which took place once a week. While the main empirical examples in this article are drawn from this one sleep lab as well as one particular interview, the broader issues I discuss also came up in my interviews with sleep doctors from other labs, in exchanges with other social scientists who work on sleep medicine in Germany (e.g. some of the authors in Ahlheim et al. 2023), and in panels and debates at the two medical conferences. In fact, many of my claims relate to general material-semiotic features of the two disorders, apnea and insomnia, as they are currently understood, treated, and enacted, by international biomedical nosologies and in medical practice (see Wolf-Meyer 2008, 2012 for similar developments in the US context). Some of my claims, however, pertain specifically to the German medical system with its particular history, economic structure and form of sleep medicine (for good overviews see Ahlheim 2018; Busse et al. 2017; Oduncu 2013). I am interested in how this German infrastructure enables, prescribes or obstructs how apnea and insomnia – due to their particular, “naturalized” properties – are dealt with by medical practitioners.

The first part of the article introduces obstructive sleep apnea<sup>6</sup> and insomnia. In the second part, I provide examples from my fieldwork and use the concept of affordance to think about the different ways doctors come to perceive, engage with, and act on these two disorders. The third part deals with the particular challenges of diagnosing sleep disorders by reflecting on the complex interplay of evidence, experience, and expertise in medical encounters. I conclude by outlining how an affordance approach can complexify our understanding of sleep (and other) disorders.

## Apnea and insomnia: Two “popular” disorders<sup>7</sup>

Apnea and insomnia are generally considered to be the two most common sleep disorders. Although such statistics need to be treated with caution, the DSM-5-TR<sup>8</sup> estimates that “across multiple countries” roughly 10% of the population meet the criteria for insomnia *disorder* (APA (American Psychiatric Association) 2022:412f). Prevalence for obstructive sleep apnea in the US is estimated to be 13–14% for men and 5–6% for women (APA 2022:431). Although comorbidity between the two disorders is common (according to German insomnia expert Crönlein (2020:41) up to 20% of insomnia patients suffer from sleep apnea), insomnia and apnea are in many ways very different illnesses and typically affect very different types of people.

According to DSM-5-TR:

the essential feature of insomnia is dissatisfaction with sleep quantity or quality with complaints of difficulty initiating or maintain sleep. The sleep complaints are accompanied by clinically significant distress or impairment in social, occupational, or other important areas of functioning. (...) [T]he *diagnosis of insomnia disorder is based on the individual's subjective perception of sleep* (...). *Subjective reports from individuals with insomnia disorder frequently indicate longer sleep latencies [i.e. time that it takes to fall asleep], greater time awake during the*

night, and less total sleep time than objective (e.g. polysomnographic) data demonstrate. The reasons for this discrepancy are not well understood. (APA 2022:411, my emphasis)

Contrary to common understandings, insomnia is less defined by a lack or poor quality of sleep than by a fundamental gap between the amount of sleep that is desired and that which can be achieved. As the above definition implies, insomnia is primarily about how the patient evaluates their sleep (i.e. as not satisfying), irrespective of the actual sleep time or quality. Predisposing and precipitating causes of insomnia can include a whole range of bio-psycho-social factors like genetics, pain, apnea, restless legs, menopause, stress, major life events or life changes. Factors that perpetuate insomnia are primarily cognitive and/or behavioral. They include, for instance, negative associations with sleep and the sleep place, increasingly irregular sleeping times (e.g. patients try to nap during the day to catch up on sleep but then have even more trouble falling asleep at night), and obsessive worrying about sleeplessness. Although hyperarousal – a psycho-physiological state of chronic tension that affects hormone levels, heart rate, and brain activities – is seen as an important explanatory factor, insomnia is generally categorized as a psychological disorder (APA 2022:409–417; Crönlein 2020).<sup>9</sup> While pharmaceutical treatment exists and is widely used, CBT-I (cognitive-behavioral therapy for insomnia) is regarded by most experts as the first-line treatment for insomnia. In practice, however, CBT-I is very hard to access in most countries, partly due to a lack of trained therapists and a lack of knowledge about CBT-I among general practitioners. Insomnia experts have consequently begun working with IT specialists to develop and promote therapy apps,<sup>10</sup> although their efficacy is still hard to assess (Baglioni et al. 2020; Koffel et al. 2018; Muench et al. 2022).

Insomnia can affect anyone, irrespective of age, gender, ethnicity or socio-economic background. Typically, however, insomnia is more common in women and is associated with particular personality features, such as being perfectionist, ambitious, anxious or (overly) health-conscious. According to Crönlein (2020:38–44), dealing with chronic insomniacs can be difficult and unpleasant because they are often desperate, demanding, and irritable. I encountered similar characterizations among the doctors I talked to in my research, who described insomnia patients as difficult, annoying, and moody. One psychiatrist put it very bluntly: “Insomnia patients,” he said, trying to find the right words, “well, they often seem very . . . emotional . . . or maybe . . . I actually perceived them as quite bitchy (*zickig*)” (INT April 2022). I will come back to this point below.

Apnea, as noted above, is in many ways quite the opposite of insomnia. According to DSM-5-TR, diagnostic criteria for “obstructive sleep apnea hypnoapnea” are defined as follows:

- (1) *Evidence* by polysomnography of at least five obstructive apneas or hypnoapneas<sup>11</sup> per hours of sleep and either of the following sleep symptoms:
  - (a) Nocturnal breathing disturbances: snoring, snorting/gasping, or breathing pauses during sleep.
  - (b) Daytime sleepiness, fatigue, or unrefreshing sleep despite sufficient opportunities (. . .)
- (2) *Evidence* by polysomnography of 15 or more obstructive apneas and/or hypoapneas per hour of sleep *regardless of accompanying symptoms* (APA 2022:429, my emphasis).

As this definition clearly shows, apnea is all about evidence. While subjective experience (e.g. of daytime sleepiness) can play a role in diagnosis if the apnea score is mild (i.e. below 15), it is irrelevant if apnea levels are higher. Apnea is a potentially serious breathing-related disorder caused by upper airway obstruction during sleep. Individuals stop breathing, several times an hour, and are then, because of drops in oxygen saturation, woken up by their brain to start breathing again. Most people do not consciously notice these brief interruptions of their sleep, but nonetheless their sleep is highly fragmented and thus unrestful (APA 2022:429–435; Galetke 2020:55–78). Although apnea officially entered medical nosologies in 1965, it remained fairly unknown until the 1990s, when more research started to be dedicated to it and medical tech companies started to develop more sophisticated therapeutic masks (Wolf-Meyer 2012:38113ff).<sup>12</sup> Since then, and related to growing levels of obesity

(one of the prime risk factors), apnea has come to be recognized as a worldwide epidemic. Sleep apnea tends to get worse with age and, if severe and untreated, can lead to hypertension, heart disease, diabetes, dementia, daytime sleepiness, and related accidents. It can cause insomnia (especially in sensitive sleepers who become aware of the recurring breathing-related sleep arousals) and other mental disorders like depression, but it is not itself a “mental disorder” in any common sense of the term.<sup>13</sup> This is also apparent when one considers the treatment options for apnea, which are all based on “physical interventions,” be it airway pressure masks (the “gold standard” treatment which, if accepted by the patient, is considered highly effective), oral appliances (like mouth guards), tongue pace-makers (an implanted medical device that reduces the occurrence of apnea by electrically stimulating the hypoglossal nerve, which causes tongue movement) or losing weight. Apnea is more common in older men and often related to obesity and/or an unfavorable throat anatomy. But it can affect anyone, including children, irrespective of weight and gender.

Apnea and insomnia are not simply “naturally given;” rather, they have emerged as medical categories over time (Lavie 2008; Summers-Bremner 2008). But while any disorder is “discursive” to some extent, here I am more interested in the actual manifestations, or affordances, of apnea and insomnia and the resulting possibilities, or challenges, for perceiving them. I focus on the different ways the two disorders, as defined by current nosologies, can be known or experienced (and, importantly, by whom) and how this matters for diagnosis and treatment. This approach is similar to work in medical semiotics (e.g. Buchbinder 2015), but emphasizes how particular “naturalized” properties of a disorder allow for, or prevent, profit-making and care-giving by the doctor within particular medical economies (here, the German one).<sup>14</sup>

### **“Good disorder,” “bad disorder:” affordances of apnea and insomnia**

Insomnia, unlike other sleep disorders, is largely an awake, first-person experience. As with chronic pain, attempts to empathize with or understand this often-tormenting experience are only ever approximations, and often fail. In fact, insomniacs commonly complain that their suffering is dismissed by others (“Don’t we all have a bad night sometimes?”) who simply cannot grasp what it feels like. Apnea, by contrast, is hardly ever consciously experienced by the (sleeping) sufferer. It can only be perceived indirectly – through awake co-sleepers, through technology, or retrospectively upon awaking and having a sense of not having slept restfully. Furthermore, due to its particular “physical” manifestation, i.e. pauses in breathing, apnea can be measured and scaled in ways that insomnia cannot. As a result of these different “affordances,” doctors can claim different levels of authority over apnea and insomnia, which, as the two vignettes in this section show, has immediate consequences for how they (can) engage with patients.

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I am sitting in the consultation room with Dr. Denisson. Once a week, she schedules appointments both for prospective sleep lab patients and for those who have already slept in the lab (to discuss their results and therapy options). I am allowed to sit in on these consultations (if patients agree), and sometimes there is time to chat for a couple of minutes in between patients. Today, Dr. Denisson is in a good mood and talks about why she likes working with apnea patients. “See this patient,” she says, referring to the man who just left, “he came it complaining about always feeling tired, saying how he had started drinking two to three liters of energy drink at work to make it through the day. But then, in the sleep lab, he tried out the mask, and he loved it. This will change his sleep, and his life!” Indeed, the patient had told us that after his first night with the mask in the lab he “had jumped through the world like a young deer” and that he could not remember when he had last felt so good and well-rested. Dr. Denisson says that apnea patients are often very appreciative and that she likes that about her work. The availability and effectiveness of mask therapy makes her feel like she can really help people. I go out to call in the next patient, a middle-aged woman who recently spent three nights in the lab. As usual, Dr. Denisson asks her what problems she is experiencing and how she came to be admitted to the lab. “Well,” the woman hesitates briefly, “I don’t really have any problems. I generally sleep fine.



But I have a new partner, and when we started sleeping together he noticed that I sometimes stop breathing during my sleep. That really scared him and he told me to go and get it checked out.” Dr. Denisson opens her file on the computer and looks at the polysomnographic results of the woman’s first “diagnostic” night in the lab. The woman has a moderate apnea score (AHI) of 20, and Dr. Denisson tells her that this is not (yet) severe but still requires treatment. Then she looks at the scores from the second night, during which the woman slept with a mask. Here, the AHI is only 3. Dr. Denisson smiles. She pulls up both images of the polysomnography and turns the screen so that the patient can see it. “See this line here,” she says, referring to the oxygen saturation measurements of the first night, “it should be straight and above 90%. But instead it is all crinkly [she uses the German colloquial term *krüselig*]. And this line here, it shows your snoring – see all these amplitudes?” Then, with great satisfaction, she enlarges the image of the second night. “But now look here. The oxygen line looks beautiful. And the snoring is almost gone. With mask therapy we can make your sleep pretty again (*den Schlaf wieder hübsch machen*)!”

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Doctors usually pursue two aims in their profession: they want to help people, and they want or need to make money. The former depends among other things on time and the availability of effective treatment. The latter depends very much on what insurance companies (or patients) are willing and able to pay for, and this is strictly regulated. For instance, Dr. Denisson told me that patient consultations should ideally take no longer than 10 minutes, for which she can charge, roughly, between 1.5 and 3 Euros. For a night in the lab, she can charge several hundred Euro. Apnea and insomnia differ not only regarding how much insurance companies “can afford” to pay for their treatments; the two disorders actually *afford* different things for doctors.

### **“Good disorders”**

The way doctors act toward a disorder is dependent on if and how they can perceive (i.e. diagnose) and affect (i.e. treat) it, whether they considered it to be serious, and on how their modes of diagnosis, evaluation, and treatment are valued, by the patient and, more importantly, in the medical economy at large. Prevalence aside, and put simply, more medical infrastructures will emerge around disorders that are easy to diagnosis “objectively,” are considered serious, and can be treated effectively than around disorders that are hard to grasp and complex to treat. Obviously, such evaluations are not static: disorders, knowledge regimes, and medico-moral economies are in constant flux, so that what is considered a “bad disease” or a “good treatment” varies between places and historical periods.

Apnea, one could argue, is a “good disease” for doctors because diagnosis and therapy are largely based on technology and thus cost-effective. Doctors can charge more for techno-based diagnosis than they can for a simple conversation. Moreover, patients’ subjective experiences do not play a significant role in doctor-patient interactions. This is good because dealing with patients’ experiences takes time, which is not paid for. Furthermore, the fact that apnea can be measured and even visualized makes it “graspable” and real for patients, even though they do not subjectively experience it. Insurance companies are willing to cover the high cost of diagnosis in the lab and subsequent mask-therapy because they are convinced that apnea is a serious illness, which, if untreated, leads to heart problems, diabetes, and dementia; problems that would cause even higher costs down the road. Mask therapy is often very successful, which, as the above vignette shows, can be a rewarding experience for both doctors and patients.

### **“Bad disorders”**

Now contrast the above vignette with the following scene that happened at the sleep lab a week later:

I have already spent a long morning observing patient consultations when Dr. Denisson calls in the last patient for today. A woman enters and I am surprised to see it is Mrs. Bennett, whom I had met, and interviewed, a few weeks earlier when she spent two diagnostic nights in the lab. We briefly nod to

each other, while Dr. Denisson looks at the file. She is running late and it is clear from her body language that she wants to get through the consultation quickly. She asks Mrs. Bennett about her medical history and reasons for coming to the lab, but cuts her off when she starts talking about her insomnia, her nightmares, and her fear of sleeping alone. As I knew from our interview, Mrs. Bennett had been the victim of a violent attack and was diagnosed with PTSD. She was about to start trauma therapy, but had been told to go to the lab to rule out any organic causes of her sleep problems. She speaks in a low voice and says that she found it very difficult to sleep in the lab. “I can see that it took a long time for you to fall asleep, but the overall sleep efficiency wasn’t that bad,” Dr. Denisson answers, without much empathy it seems to me, while studying the polysomnographic results. Ignoring Mrs. Bennett’s earlier remarks about her insomnia, Dr. Denisson then shifts the focus of the conversation to the apnea scores: the AHI is 13 for the first night, and 10 for the second night. “You should try mask therapy,” Dr. Denisson says, not mentioning the fact that the scores are in the “mild” apnea range. Mrs. Bennett seems shocked: “I cannot sleep with a mask,” she replies, “just the thought of it makes me panic. I just want the nightmares to go away so I can sleep peacefully again.” “Maybe the panic you experience in your sleep is being caused by the drops in oxygen saturation,” Dr. Denisson replies, now visibly annoyed. “If you are not even willing to try the mask, I will have to note ‘Maskeninakzeptanz’ (meaning noncompliance with recommended mask treatment) in your file and you will have to explain to your insurance company why you want alternative treatment.”<sup>15</sup> After she has dismissed a noticeably confounded Mrs. Bennett, Dr. Denisson turns to me and comments how some patients are just so whingy and that it is very difficult to help them.

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As Lester’s (2009) analysis of eating disorder treatment in the US shows, the desire of doctors to act ethically and help their patients is often compromised by the larger medical economy, which values cost efficiency over “doing good,” and categorizes disorders accordingly. While the German medical economy is certainly more inclusive than the US managed-care system (Busse et al. 2017), it still imposes many constraints on doctors’ ability to provide good care, a major one being the very limited amount of time a doctor can dedicate to each patient.<sup>16</sup> Doctors, as Lester convincingly demonstrates, sometimes cope with their frustration and failures to provide good treatment by blaming the patient. Dr. Denisson’s behavior in the scene above could be interpreted against this background.

Insomnia is a profoundly subjective illness and therefore, one could say, a “bad disease” for doctors. Many of the doctors I talked to described insomnia patients as difficult, not only because they are often moody due to lack of sleep, but also because insomnia is hard to diagnose “objectively,” and it is even harder to provide patients with adequate treatment. Dealing with insomnia, for doctors, is certainly not cost-effective because, ideally, both diagnosis and therapy depend on talking (which takes time and is not well-paid unless one is a registered psychotherapist; more on that below). Nevertheless, most doctors I met, including Dr. Denisson, wanted to help their sleep-deprived patients and tried to find ways to “do something” within the parameters set by the medical system. I sometimes observed, as in the vignette above, that doctors tried to treat insomnia “as apnea” by effectively reducing patients’ insomnia experiences to (potentially) co-occurring apnea. This, then, enabled them to justify diagnosis in the lab and prescribe “techno-therapy” (e.g. masks), which was much easier to access than CBT-I and less invasive, less controversial, and less addictive than psycho-pharmaceuticals.<sup>17</sup> However, insomniacs, for obvious reasons, were often quite reluctant to try mask therapy, because masks were perceived as a further, major disturbance of their attempts to sleep (cf. Crönlein 2020:39f).

As mentioned in the previous section, the “treatment gap” for insomnia, for which effective, evidence-based therapy exists in theory, is a well-known and much-discussed problem among insomnia experts. According to the medical literature, and based on my own observations and conversations with sleep doctors, insomnia patients often did not receive adequate treatment for four main reasons: a) They did not know where to go, and/or felt that their sleep problems did not deserve a doctor’s attention, and/or hoped that their sleep would simply get better again by itself; b) their problems were not taken seriously enough, or underestimated, by doctors; c) CBT-I, but also cognitive-behavioral therapy more generally, was in short supply; and d) psychologists and



psychotherapists, i.e. those professionals who are trained and paid to talk to patients about subjective experiences, were often reluctant to accept insomnia patients unless they met criteria for depression or anxiety, disorders which they considered more serious. One psychologist, the acting director of one of the very few neuro-psychiatric labs in the part of Germany where my research is located, told me:

Insomnia patients really fall through all cracks in the German medical system. They sometimes end up here after a long odyssey, after they have been to other doctors and other sleep labs, none of which could help them. Many don't fulfill the criteria for depression, so that psychologists reject them after the intake screening. Sometimes they can be diagnosed with an anxiety or adaptation disorder, and access therapy through that. But for many that does not work either, and waiting times for CBT are a year and more in any case. I sometimes refer patients for therapy, but often they come back and report that the psychologist told them that their suffering is not serious enough or simply that they have to prioritize others. Even for me here, at the sleep lab, there is not much I can do: I cannot admit insomnia patients long-term, and it is very hard to bill insurance companies for outpatient treatment. Many come for consultation, but I increasingly have to reject them. (Interview April 2022)

As this quote highlights, medical infrastructures for apnea and insomnia treatment in Germany are very different. While more or less every apnea patient who wants treatment can receive mask therapy, very few insomnia patients can access the type of therapy that is considered most effective. And while apnea patients receive treatment for apnea itself, insomnia patients often qualify for treatment only if they also present with symptoms of other disorders, such as apnea or depression. Such discrepancies in the availability of treatment are not self-evident. They result, in part at least, from the different affordances the two disorders offer for doctors, and how doctors and other actors in the medical system have “learned” to act on these affordances.

### **Medical affordances**

The concept of affordance was initially developed by ecological psychologist Gibson (1979) to think about naturalistic environments and what they “afford” animals. Against mainstream cognitive psychology at the time, which proposed that perception was an activity of the mind, Gibson claimed that perception is the achievement of a whole living organism (what today one might call body-mind) that is actively engaged in its surroundings (Ingold 2022:52). In recent times, the concept has become popular in anthropology and other disciplines (Djebbara 2022). Sometimes diverging from, or extending, Gibson's original formulation, scholars have appropriated the concept for various purposes: for instance, to think about the interactability between systems or organisms; to theorize the relationship between perception and action; and/or to analyze properties of a given environment or object and what they offer for an inhabitant or user.

Here, I propose the term medical affordance to think about disorders in the context of medical economies. Medical affordances describe what different disorders offer for those who engage with them (in this case, the doctor). Put simply: how a disorder is, or can be, perceived matters for the ways doctors and other medical experts (can) deal with it.

One affordance of apnea is that it is measurable: apneas can be counted. Diagnostic technology, whose use is generally profitable for doctors, can help to measure and analyze apnea “in context” (i.e. in what phase of sleep apneas occur, in which sleeping position, for how long, with which impacts on oxygen saturation, etc.). Doctors perceive apnea as an observable “thing:” they can see it on their monitors, hear it through their microphones, and they can later show it, in graphs and figures, to their patients. Furthermore, and related, doctors also feel like they can “act on apnea” in a fairly straightforward way. Mask therapy, in most cases,<sup>18</sup> successfully eliminates apnea and thus contributes to “making sleep pretty again.” Patients, if willing, can be helped, *and* doctors are financially rewarded for their work.

Insomnia, by contrast, makes it hard for doctors to meet either of these conditions. Insomnia is not measurable in any strict sense of the term; it is hard to grasp “objectively,” and hard to eliminate. Because it is hard for doctors to perceive insomnia, patients sometimes feel that the profound suffering they experience is not taken seriously. Furthermore, as Crönlein (2020:49) writes, many insomniacs have already undergone a certain “chronification” of the disorder by the time they finally decide to see a doctor. They come across as desperate, grumpy, and unappreciative because they have often already tried different measures (like self-medication) in vain. They are thus worried, often rightfully so, that the doctor will not be able to help them either. This is another contrast to apnea patients, who often find out about their disorder for the first time through the doctor, and are then offered immediate help.

### **Evidence, experience, expertise: On (Mis)perceptions and the challenges of diagnosis**

Diagnosis is a particular form of generating knowledge, usually based on a mix of anamnesis (i.e. narrative) and technology-based bodily assessment. It relies, where possible, on scientific evidence<sup>19</sup>: blood tests, x-rays, or in the case of sleep disorders polysomnography. But diagnostic knowledge is always also affected by both the doctors’ and patients’ embodied experiences and the atmosphere of their encounter. For instance, doctors might find patients moody or difficult and therefore dismiss their suffering; conversely, patients might lack trust in the doctor and thus question medical knowledge.

Medical encounters are based on complex interplays of patient experiences, doctors’ expertise and culturally specific institutional frameworks, and they often involve attempts to reconcile subjective meanings and sensations with “objective” physiological evidence (e.g. Laing 1967; Good 1994; Kleinman and Kleinman 1991; Kleinman 1988; or, more recently; Mulla 2014; Sterne 2021). Successful medical encounters are those in which evidence, expert knowledge, and patient experience concur, as when I experience pain in my tooth, the doctor detects a hole, and I agree that this is a legitimate assessment of my problem. Often, however, and even within a shared cultural system, evidence, knowledge, and experience do not neatly align, or they even contradict each other: I don’t feel ill but the doctor detects a tumor, or I am sure something is medically wrong with me but the doctor cannot find anything. In apnea, as we have seen, evidence usually “trumps” experience. Doctors can know (i.e. observe and measure) apnea in a way sleeping patients cannot. In insomnia, by contrast, subjective experience is more important than medical evidence. In fact, it is the prime diagnostic criterion: a patient can suffer from insomnia even if their sleep quality and quantity is objectively fine.

In sleep disorders, the potential tensions between evidence and experience are exacerbated by the fact that sleep creates substantial limits for experience.<sup>20</sup> As Leder writes:

Sleep is precisely a withdrawal from experience (. . .) In deep sleep, interoception, proprioception, exteroception – all recede. My own sleeping body is one thing I will never directly see. Where “it” is, “I,” as conscious, perceiving subject, necessarily am not. (. . .) [However], modes of indirect perception remain. Upon awakening in the morning I can infer from the light outside, the shape of my bedclothes, and my current bodily feelings something about the length and quality of my sleep. Or I can learn it indirectly through another. I am the one person who will never be able to hear myself snore, but my wife will describe it in no uncertain terms. (Leder 1990:57f)

Sleep researchers are developing ever more sophisticated technologies for measuring and evaluating sleep. But how this knowledge relates to people’s experience of sleep is a complex, largely unresolved question and often a point of contention between sleep doctors and their patients. While technology sometimes helps to translate experience into evidence, it can also further obscure it, as the following example shows.

## A sleep doctor without a lab

Dr. Speke is one of the few psychiatrists who specializes in sleep disorders. For many years he had run the sleep lab at a university-based psychiatric clinic where he worked as an *Oberarzt* (senior physician). In 2019, he left the clinic to become the head of a psychiatric hospital which, like most psychiatric hospitals in Germany, did not have a sleep lab.<sup>21</sup> Although his work now focuses mostly on other things, he is still passionate about sleep medicine and research. Once a week he offers a *Schlafsprechstunde* (sleep consultation) for people suffering from sleep problems. Now without a lab, he has to rely solely on the patients' reports, and his own long-term experience as a sleep doctor, when diagnosing and recommending treatment. With a chuckle, he told me in our interview:

I now have this interesting situation of doing sleep medicine without a sleep lab. Before it was different: when a patient came to see me and I wanted to engage with them, I had to justify to the clinic that I would use time and resources. In order for the clinic to get at least a few hundred euros from the insurance company, I had to send the patient to the sleep lab; so that my efforts – talking to the patient, writing the report etc. – would be paid for. Now here, for my *Schlafsprechstunde*, I can only charge a standard “flat fee” (*Pauschale*). So to give you an example: a young man comes with his girlfriend and tells me that he has a strange, and embarrassing, problem: At night, he sometimes walks through the apartment, not fully awake, and sits down to urinate in random places. To me it is clear: he is a sleep walker. At the university clinic, I would have told him: “Well, probably you are sleep walking, but it would be good to check this out thoroughly. We will need you to sleep at our lab for at least three nights, because it usually takes a while to capture sleep walking.” Then he would have slept at the lab, and afterwards I would have looked through his polysomnographic results, fascinated and curious. In those sleep phases, where the figures indicate that something happened, I would have consulted the video material, and would have been happy like a detective to find the proof for my diagnosis! I could have then also used the case to demonstrate to my students what sleep walking looks like, how and in what phase of sleep it occurs, etc. And I would have called in the patient for another consultation, during which I would have shown and explained the evidence to him. Here, in this clinic, I don't have any of that. I have to be satisfied with what patients report. And then, based on my experience, I can say that, yes, this is sleep walking. Period! I don't have all the technology, but it works nevertheless. So ... how you do diagnosis always depends on the external circumstances.

He continued to talk at length about the different roles experience or evidence can play in the diagnosis of sleep disorders.

“Sleep is fascinating,” he said with a big smile, “because you can even observe psychological states directly! I can sit in front of the monitor and then I see – *zick zack zick zack* – rapid eye movements to the left, and I think: wow, he is dreaming of something that is happening there on the left. You have a very close view into the brain. It's truly fascinating. And you can generate a lot of data. But in the end, what you can really do with the data is always a bit disappointing. I will tell you my favorite story: One day a patient came to see me here. She said I was her last resort. Everyone thought she was hysterical. Well, she actually was hysterical, she had a histrionic personality disorder. She told me she suffered from narcolepsy<sup>22</sup> but that no one believed her. She had already been to a highly renowned sleep lab and she had brought along the reports which had been written by very experienced colleagues.”(..)

He explains that the report showed that the diagnostic test they had done in the lab had been negative. This multiple sleep latency test measures how quickly a patient falls asleep in a monotonous situation. Narcoleptics usually fall asleep very quickly, but this woman said she was too nervous about the test to fall asleep. Even though, according to the report, the woman had been able to describe certain features of narcolepsy – like cataplexy – which she claimed to experience, the doctors at the lab did not find her accounts credible and refused to do further tests.

So when she first came in and I saw the reports, I thought dismissively: “Yeah yeah, sure, no one believes you ...” But then, when I listened to how she described her symptoms, I changed my mind. What she described was so typical and specific. Unless she had thoroughly studied medical textbooks, she would not have been able to describe narcolepsy so accurately. So I told her. I said, “I believe you, maybe we can do some further tests.” [There is now a hormone-based test which can more reliably detect narcolepsy]. When she heard that, she became very emotional. As you may know, cataplexies are triggered by emotional arousals. And then she had a cataplexy right there in front of me, because she was so relieved! These are rare occurrences, which you don't often encounter as a sleep doctor. Then we did the hormone test and it showed a very low level of hypocretin and so confirmed the diagnosis. So, this is an example of how being too fixated on technical operations can lead to misdiagnosis. It is

well-known that the multiple sleep latency test is not a hundred percent accurate. But if you trust technology and simply dismiss a patient's report, just because she seems a bit hysterical, you can end up with the embarrassing result of overlooking a clear case of narcolepsy.

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It is always a challenge for medical encounters when evidence, experience, and expertise do not align. Contradictions between what a patient experiences and what a doctor can observe, or between something a doctor has detected but a patient does not perceive, are very common and can be interpreted in different ways. For instance, a patient may think that the doctor is incompetent, but the doctor may accuse the patient of malingering. A well-established, but increasingly challenged, distinction between “evidence-based” disorders and those that are harder to grasp is that between physical and psychological disorders. Tumors, broken bones, or viruses can be perceived by doctors in ways that depression, anxiety or insomnia cannot. Although, since at least the publication of the DSM III in 1980, medical experts have tried to render so-called mental disorders more measurable, “objectifiable,” and biological,<sup>23</sup> symptoms that are hard to “verify” (like sadness, phantom pain or disturbed sleep) are still generally considered psychological, and sometimes, as in the case above, dismissed as hysteria.

Conversely, medical evidence “without experience” may lead a patient to question or reject a doctor's diagnosis. Most patients, however, when confronted with perceptible proof (such as polysomnographic graphs, images of a tumor, heartbeat sounds, etc.), at least seriously consider the evidence and the doctor's expert recommendations. From my experience, for instance, some apnea patients initially found it hard to accept their diagnosis and argued with the doctor. In the end, however, almost everyone agreed to try some form of therapy.

Experience without “proper” evidence is a more complicated constellation that is exacerbated by the power imbalances between the doctor as authority and the patient as “help-seeking subject.” Patients need to appear credible and “convince” doctors of their suffering; in turn, doctors rely not only on their professional expertise but also on their experience of the patient. Experience-based diagnosis requires different (especially interpersonal) skills than evidence-based diagnosis, which usually relies heavily on technology (Buchbinder 2015). While many doctors (still) possess these interpersonal skills, and are often committed to applying them, such experience-based forms of diagnosis, as my examples indicate, are not highly valued in biomedical economies. In the words of Taylor (2020:28):

Younger physicians (. . .) have been trained and socialized to use increasingly sophisticated diagnostic equipment. The reimbursement incentives and liability environment further enable this trend. This results in a general degradation of history taking and the physical examination of patients. The cornerstones of the doctor-patient relationship, the human interaction skills, are being forgotten. Many economic, social, and political forces across the board shape what we know, what we are taught not to know or value.

This assessment of the US context seems equally applicable to the German medical system where proven clinical evidence and cost-effectiveness to a large extent determine what counts as good medical practice (Oduncu 2013:336).

## Conclusion

The theory of affordances (. . .) leads us to see difference as emergent from within the nexus of our practical involvement with beings and things in the world around us, and in the variable skills of perception and action to which it gives rise. (Ingold 2022:55)

In the German medical economy, sleep disorders like apnea, which can be perceived by the doctors through concrete evidence generated by technological assessment, have a higher chance of receiving treatment than disorders like insomnia, which rely on more time-consuming and less profitable “experience-based” forms of diagnosis and treatment. Apneas can be heard and visualized, measured

and scaled, and they can be effectively “eliminated” through treatment. Insomnia, by contrast, is a particular form of experiencing and making sense of sleeplessness, which may, but often does not, neatly correspond to actual sleep figures, and is thus hard to measure or compare. One person may frequently lie awake all night without overly suffering; another may develop insomnia despite regularly sleeping several hours.

Since its beginnings in the early 1990s, German sleep medicine has undergone a continuous “pneumologization” (as some of my interlocutors called it). In the early days interdisciplinary cooperation was common, even within individual labs, thus enabling more comprehensive forms of diagnosis and treatment.<sup>24</sup> Nowadays, however, labs are much more specialized, and most are run by pneumologists and focus on apnea. Pneumologists, as one of my interlocutors explained, saw not only the medical necessity but also the economic potential of large-scale apnea interventions, and actively lobbied for significant changes in the fee schedule (*Abrechnungsmodalitäten*) to render diagnostic procedures (i.e. polygraphs and polysomnographies) and treatments (especially mask therapy) billable with the insurance companies. Psychologists and psychiatrists, by contrast, withdrew from or were gradually driven out of sleep medicine (my interlocutors expressed different perspectives on this). They did not see, or did not want to create, ways to make disorders like insomnia more medically significant, and have so far never attempted to include possible diagnostic instruments (like actigraphy) in the EBM.<sup>25</sup>

Affordances, as this shows and Ingold (2022) notes, develop in interaction with ever-changing environments. New developments in sleep technologies – especially the emergence of monitoring and therapeutic apps, but also the approval of new medications<sup>26</sup> – may change how sleep disorders can be perceived, by whom, and how this affects profit-making. Pneumological sleep labs, and the doctors who run them, may eventually become redundant if apnea screenings can be done via smart phones at home. Conversely, new medications may affect the treatability of insomnia and thus render the disorder (and the patients who suffer from it) more manageable for doctors. Affordance theory, then, provides yet another lens on a problem that lies at the heart of medical anthropology: how, why, and which disorders emerge in particular times and places depends on their perceptibility – and on whether perceiving them or not is of interest, and for whom.

## Notes

1. All names have been changed and some details fictionalized so as to prevent individuals from being identifiable. The research language (with very few exceptions) was German. The translations in this article are my own. Ethical clearance was provided by the Max-Planck-Institute in line with current guidelines of the German Anthropological Association. Written consent was obtained from all research participants.
2. Sleep apnea is a potentially quite serious breathing-related sleep disorder, whereby people stop breathing – often several times an hour and usually without noticing it themselves – during their sleep. The Apnea Hypopnea Index (AHI), expressed as the number of apneas or hypoapneas (i.e. breathing irregularities) per hour, is used to classify the severity of apnea as follows: None/Minimal: AHI < 5 per hour; Mild: AHI ≥ 5, but <15 per hour; Moderate: AHI ≥ 15, but <30 per hour; Severe: AHI ≥ 30 per hour.
3. Sleeping sounds (snoring in particular) are among the parameters assessed in a polysomnography (see footnote 4).
4. The polysomnography is a multi-parameter assessment which is used to diagnose sleep disorders. It records, for instance, brain waves, oxygen saturation, eye and leg movements, and breathing.
5. Airway pressure masks deliver a stream of oxygenated air into the patient’s nose and/or mouth and thus prevent airways from collapsing and obstructing breathing during sleep.
6. Obstructive sleep apnea is the most common form of sleep apnea and the focus of this article. As the name suggests, apnea is caused by obstructions of the upper airways. Central apnea, the less common form, results from neurological irregularities whereby the brain stops sending proper signals to the muscles that control breathing.
7. I am playing on the German term *Volkkrankheit* here which designates society-wide health concerns, but literally translates as “popular disease.”
8. Diagnostic and Statistical Manual of Mental Disorders. Fifth Edition. Text Revised, published by the (APA American Psychiatric Association 2022). I am using the DSM because it provides up-to-date (2022) diagnostic criteria and, furthermore, is also a statistical manual which, despite its prime focus on the US, is commonly used in international mental health research. Other nosologies used for diagnosing sleep disorders include the ICD (International Classification of Diseases, most recent version published in 2022 by the WHO) and the ICSD

(International Classification of Sleep Disorders, latest version published in 2014 by the American Academy of Sleep Medicine).

9. Physical causes are thus sometimes overlooked (Crönlein 2020: 41).
10. <https://somm.io/en/>, accessed 03.11.2022. Somnio, is the first insomnia app in Germany which can be prescribed and is then paid for by insurance companies, a so-called *digitale Gesundheitsanwendung* (digital health application).
11. Hypoapneas are defined by reduced breathing and oxygen saturation. In contrast to apneas, however, breathing does not stop completely.
12. In Germany, too, sleep labs and sleep research, especially on sleep apnea, started to take off on a larger scale only in the early 1990s (Interview with Doctor S., March 2022).
13. As such, it is quite surprising that it is listed in the Diagnostic and Statistical Manual of *Mental Disorders*.
14. For more information about the particularities of the German medical system/economy see for instance (Altenstetter 2003; Niewöhner et al. 2011) and (Oduncu 2013).
15. Usually, insurance companies require apnea patients to try mask therapy first before they are willing to fund alternative treatments such as oral appliances or tongue pace makers. If patients have tried masks, but cannot tolerate them, this is called “Maskenintoleranz” (mask intolerance). If patients are unwilling to try masks at all, this is called “Maskeninakzeptanz” (mask unacceptance).
16. A recent study found that in Germany doctors only have an average of 7,6 minutes per patient, much less than in most other European countries (Stucke and Enwaldt 2023).
17. In Germany, sleeping pills have quite a negative reputation: because they have a high risk for addiction, because they often come with undesired side-effects and because they mainly treat the symptoms, but not the causes of insomnia. Thus, many doctors are reluctant to prescribe them and many patients refuse to take them. Unlike in the US, where direct-to-consumer marketing of pharmaceuticals is widespread and sleep medication is relatively easily accessible (Wolf-Meyer 2009), the regulation of pharmaceuticals, generally and for sleep disorders in particular, is very strict in Germany.
18. For a more complex reading see Vorhölder (2023).
19. What counts as evidence obviously varies between different medical systems. In this article, I focus solely on biomedical contexts and biomedical notions of evidence.
20. Phenomenologists have long grappled with sleep as a “limit problem” and debated whether, and if yes how, sleep can be conceptualized as a form of experience (e.g. De Warren 2010; Heyes 2020; Leder 1990; Mensch 2022).
21. As one psychiatrist explained to me (INT April 2022), it is very hard – for psychiatrists – to cost-efficiently run a sleep lab. The one at Dr. Speke’s previous hospital was shut down for this reason after he left.
22. Narcolepsy is a chronic sleep disorder characterized by overwhelming daytime drowsiness and sudden attacks of sleep. People with narcolepsy often find it difficult to stay awake for long periods of time, regardless of the circumstances. Sometimes, narcolepsy can be accompanied by a sudden loss of muscle tone (cataplexy) (<https://www.mayoclinic.org/diseases-conditions/narcolepsy/symptoms-causes/syc-20375497>, last accessed 08.11.22).
23. This is being taken to a whole new level by current attempts to replace the DSM with the so-called Research Domain Criteria Initiative, see <https://www.nimh.nih.gov/research/research-funded-by-nimh/rdoc>, last accessed 07.11.22.
24. In those days, as one of my interlocutors (a psychologist) told me, it was even possible for a psychologist to run the sleep lab at a lung clinic which, today, “would be unthinkable.” One of the main caesuras was the introduction of the “sleep doctor qualification” in 2005, which is open to medical doctors, but not to psychologists. As a consequence, it has become much harder for psychologists to bill insurance companies for sleep disorder treatments (telephone interview with Doctor F., April 2022).
25. Actigraphy is a method of monitoring rest/activity cycles, usually by means of a wristwatch-like motion-sensing device. The “Uniform Value Scale” (*Einheitlicher Bewertungsmaßstab*—EBM) determines the relative weight of all health care services and regulates how, and for what, physicians are reimbursed (<https://www.bundesgesundheitsministerium.de/service/begriffe-von-a-z/e/einheitlicher-bewertungsmaassstab-ebm.html>, accessed 06.03.23).
26. At the 2022 annual conference of the German Sleep Society a new insomnia medication was launched for the German market, which – so experts hoped – would revolutionize insomnia treatment and eventually replace CBT-I as the first-line approach.

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## Notes on contributor

*Julia Vorhölder* is a senior research fellow at the Max Planck Institute for Social Anthropology in Halle (Saale), Germany. She has conducted extensive fieldwork in Uganda on a wide range of topics, including perceptions and contestations of socio-cultural change, post-war humanitarian interventions, gender and generational relations, and – most recently – emerging forms of psychotherapy. Her new research project is based in Germany and focuses on experiences, assessments, and treatments of sleep disorders and how these are negotiated between doctors and patients. Julia obtained her PhD from Göttingen University in 2014 and her Habilitation from Leipzig University in 2021.

## ORCID

Julia Vorhölder  <http://orcid.org/0000-0003-1343-9920>

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