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# Insomnia identity

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#### ABSTRACT

Insomnia identity refers to the conviction that one has insomnia, and this sleep complaint can be measured independently of sleep. Conventional wisdom predicts that sleep complaints are synchronous with poor sleep, but crossing the presence or absence of poor sleep with the presence or absence of insomnia identity reveals incongruity with expected patterns. This review of existing research on insomnia identity processes and influence finds that about one-fourth of the population are uncoupled sleepers, meaning there is an uncoupling of sleep and sleep appraisal, and daytime impairment accrues more strongly to those who endorse an insomnia identity. Research supports the conclusion that there is a cost to pathologizing sleep. Individuals claiming an insomnia identity, regardless of sleep status, are at greater risk for a range of sequelae including self-stigma, depression, suicidal ideation, anxiety, hypertension, and fatigue. A broad research agenda is proposed with hypotheses about the sources, clinical mechanisms, and clinical management of insomnia identity.

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People with insomnia construe particular significance from nighttime wakefulness. In the dark, in the quiet, in the lonely stillness, the aggrieved struggle to rescue sleep from vigilance. But insomnia impact isn't confined to sleep. Nighttime hardship taints daytime experience, inciting anticipatory worry and self-defeating compensatory behaviors (Harvey & Spielman, 2011). Insomnia is a 24-h disorder characterized by dreary quality of life (Riedel & Lichstein, 2000). Though just as informative, some impute less insidious meaning from blemished somnolence (noncomplaining poor sleepers) and others ascribe sleep pathology when none is apparent (complaining good sleepers).

Insomnia is a sleep disorder, but it also may be a cognitive appraisal disorder. Two salient questions arise: how does one arrive at the conclusion that one is an insomniac and what are the consequences of this realization? This paper investigates a neglected cognitive aspect of insomnia in the hope of narrowing the gap between insomnia treatment goals and outcome. The premise of this paper is that the self-attribution of the insomnia label, termed insomnia identity, instigates a cognitive process that is predictive of the disorder and degrades quality of life. Further, it is hypothesized that insomnia identity is a drag on sleep treatment progress, beckons relapse, and commands intervention attention.

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Interest in insomnia identity originated with the unexpected report that not all people with poor sleep report sleep distress (Fichten et al., 1995). Daytime impairment was likely to occur only when poor sleep was accompanied by sleep dissatisfaction. Daytime impairment was a function of one's attitude about sleep, not sleep. We have adopted the inclusive term insomnia identity to capture processes and effects associated with sleep dissatisfaction. It is now clear that the basis for adopting an insomnia identity is ironically often disengaged from sleep pattern. Research has given credence to the terms complaining good sleepers, people whose sleep does not satisfy insomnia conventional benchmarks but who insist they have insomnia, and noncomplaining poor sleepers, people whose sleep satisfies most insomnia conventional benchmarks but who are content with their sleep. Pathologizing sleep, i.e., embracing an insomnia identity, is only partly determined by one's sleep pattern. This article is a literature review of research exploring the characteristics and implications of insomnia identity.

### 1. Insomnia identity defined

Labeling oneself an insomniac creates an insomnia identity. Global complaints of poor sleep and general statements of sleep dissatisfaction are equally taken as evidence of insomnia identity. Determining the origin of insomnia identity is elusive, but plausible candidates can be eliminated. Data given below bolster the unlikely conclusion that insomnia identity is indifferent to the presence of good sleep.

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#### **Abbreviations**

CBTi Cognitive Behavior Therapy for Insomnia

CG complaining good sleeper
CP complaining poor sleeper
CTi Cognitive Therapy for Insomnia
NG noncomplaining good sleeper
NP noncomplaining poor sleeper

NRS Nonrestorative sleep
PSG polysomnography
SE sleep efficiency
SOL sleep onset latency
TST total sleep time
TWT total wake time

WASO wake time after sleep onset

For purposes of isolating insomnia identity from poor sleep, it is critical to evaluate sleep and sleep complaint independently. For example, if an individual reports difficulties falling asleep, that conflates poor sleep with a sleep complaint. This approach confounds sleep assessment with a valenced view of sleep. Present purposes would require that we ask the subject 'how long does it take you to fall asleep,' a nonjudgmental assessment. We would then ask "are you dissatisfied with your sleep?" The studies reported herein succeeded in this dual approach to assessing sleep and sleep complaint. Typically, sleep was evaluated by PSG or sleep diaries and sleep complaint by inquiring about sleep dissatisfaction.

We have used two assessment devices to establish the presence of an insomnia identity. Originally, we asked respondents to list any sleep disorders they might have (Lichstein, Durrence, Riedel, Taylor, & Bush, 2004). If they claimed insomnia, we presumed an insomnia identity. Others have used similar approaches to determine the presence of an insomnia self-concept (Edinger et al., 2000; McCrae et al., 2005).

Our current research assesses insomnia identity more formally and directly with a Likert scale: I am an insomniac (with choices): Strongly disagree, Disagree, Undecided, Agree, Strongly agree. We are also exploring an alternative stem: I have insomnia, hoping to clarify the best way to capture this characteristic. The Likert approach recognizes that insomnia identity strength is graded.

We chose the term insomniac in the stem because we believed it would be more difficult to endorse than 'insomnia' and would betray a stronger insomnia identity presence, even though calling a person by their disorder is rightfully viewed as offensive by many. However, we are not calling people 'insomniac.' We are asking them if they call themselves that. The label insomniac beckons a durable, trait conceptualization compared to a more pliable state of having insomnia. We have not compared the two stems and do not know which is more revealing. The adequate assessment of insomnia identity remains an open question.

Indeed, the adequate assessment of what constitutes good and poor sleep for an individual is also elusive. Determining idiographic sleep status by applying nomothetic standards does not ensure a good fit. I return to this topic in the Discussion.

Individuals may or may not have poor sleep and may or may not complain of poor sleep. Crossing sleep status with complaint status yields four distinct groups, but there are not standardized terms for these groups and inconsistent language obscures clarity of communication. For example, individuals who exhibit poor sleep but do not view themselves as having a sleep problem have been called low distress poor sleepers (Fichten et al., 1995), subjective

normal sleepers (Edinger et al., 2000), and noncomplaining poor sleepers (Lichstein, Durrence, Taylor, Bush, & Riedel, 2003).

Fig. 1 portrays the four types of match and mismatch that might occur when considering the presence or absence of poor sleep and sleep complaints. Isomorphic quadrants 1 (CP, complaining poor sleeper) and 4 (NG, noncomplaining good sleeper) capture the common understanding of insomnia and normal sleep, respectively. The highlighted off diagonal quadrants 2 (NP, noncomplaining poor sleeper) and 3 (CG, complaining good sleeper) depict sleep/complaint incongruity, the unlinking of sleep and sleep complaint. I refer to these individuals as uncoupled sleepers. This paper will adopt these terms, rather than repeatedly having to describe common characteristics of disparate terms across studies.

#### 2. The stigma of insomnia identity

#### 2.1. Labeling

The stigma associated with mental illness diagnoses is long-standing, widespread, and well documented (Hinshaw, 2007). There are many reasons why stigma occurs. Typically, it originates with observation or anecdotes of unconventional behavior, but is compounded by the observer inferring unfounded character flaws, including poor self-control and responsibility avoidance.

#### 2.2. Self-labeling

Self-stigma occurs when negative stereotypes are internalized attendant to a professional diagnosis or when the diagnosis is self-conferred. Self-labeling creates stigma-induced distress similar to labeling from others, including low self-esteem, shame, restricted constructive activity, and bridled help-seeking (Corrigan & Watson, 2002; Corrigan, 2004; Pattyn, Verhaeghe, Sercu, & Bracke, 2014). Milder psychiatric conditions, including insomnia, are concealable (Hinshaw, 2007). Individuals can elect not to disclose its presence to others to elude stigma, but then may endure the anxiety of secretive identity, deceit, and fear of discovery.

## 2.2.1. Self-labeling and insomnia

As documented below, insomnia presents a distinctive self-labeling environment because the majority of people with disturbed sleep do not seek professional help, and when they do, the diagnosis of insomnia is almost always initiated by the patient. Thus, people who adopt an insomnia identity account for virtually the entirety of the treated and untreated population of people with insomnia.

Four studies investigated stigma in insomnia using four methodologies: focus groups (Carey, Moul, Pilkonis, Germain, & Buysse, 2005; Kyle, Espie, & Morgan, 2010), audio diary (Kyle et al., 2010), individual interviews (Henry, Rosenthal, Dedrick, & Taylor, 2013), and questionnaires (Stinson, Tang, & Harvey, 2006). The most common stigma related reports were feeling misunderstood by peers and healthcare providers, their complaints were trivialized by others, and their sleep problem fostered social isolation (Carey et al., 2005; Henry et al., 2013; Kyle et al., 2010). People with insomnia reported shame when talking about their sleep problem (Henry et al., 2013; Kyle et al., 2010), and reported that anticipated stigma discouraged them from seeking treatment (Henry et al., 2013; Stinson et al., 2006).

#### 2.2.2. Constricted treatment seeking in insomnia

Treatment exposure for the majority of people with insomnia is limited to over-the-counter hypnotics, alcohol, or self-help media (Johnson, Roehrs, Roth, & Breslau, 1998; Morin, LeBlanc, Daley, Gregoire, & Merette, 2006). Survey estimates reveal 52–84% of

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