



## Unique sleep disorders profile of a population-based sample of 747 Hmong immigrants in Wisconsin

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### ARTICLE INFO

#### Article history:

Available online 2 July 2012

#### Keywords:

USA  
Sleep disorders  
Sleep paralysis  
Hmong health  
SUNDS  
Sleep apnea  
Cultural stress  
Brugada syndrome

### ABSTRACT

Concerns regarding sleep disorders in Hmong immigrants in the US emerged when an astonishingly high mortality rate of Sudden Unexplained Nocturnal Death Syndrome (SUNDS) was documented in Hmong men. Stress, genetics, and cardiac abnormalities interacting with disordered sleep were hypothesized as contributing factors to SUNDS. Most recently, sleep apnea has been implicated in nighttime deaths of Brugada Syndrome. This syndrome is thought to comprise a spectrum of sudden cardiac death disorders, including SUNDS. However, little research since has placed SUNDS in its context of Hmong cultural beliefs, health, or the prevalence of other sleep disorders. Because the epidemiology of sleep disorders and terrifying nighttime experiences in Hmong is poorly documented, we investigated the prevalence and correlates of sleep apnea, rapid eye movement (REM) sleep stage related disorders, and insomnia in 3 population-based samples (collected from 1996 to 2001) comprising 747 Hmong immigrants in Wisconsin. Participants were questioned on sleep problems, cultural beliefs, health, and other factors. A random subsample ( $n = 37$ ) underwent in-home polysomnography to investigate sleep apnea prevalence. Self-report and laboratory findings were compared with similarly collected data from the Wisconsin Sleep Cohort (WSC) study ( $n = 1170$ ), a population-based longitudinal study of sleep. The results inform a unique Hmong sleep disorder profile of a high prevalence of sleep apnea, sleep paralysis, and other REM-related sleep abnormalities as well the interaction of culturally related nighttime stressors with these sleep problems. For example, experiences of *dab tsog* (frightening night spirit pressing on chest) was prevalent and related to sleep apnea indicators, sleep paralysis, nightmares, hypnogogic hallucinations, and insomnia. Understanding the role of sleep disorders and the cultural mechanisms that may trigger or condition response to them could ultimately provide a basis for screening and intervention to reduce the adverse health and emotional consequences of these conditions in Hmong.

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### Introduction

#### *Sudden Unexplained Nocturnal Death Syndrome (SUNDS)*

In 1981, an unusual new condition came to the attention of the medical community: based on mortality reports first appearing in 1977, the Centers for Disease Control (CDC) issued an international note that Southeast Asian refugees, primarily Hmong, to the US were dying in their sleep (Centers for Disease Control, 1981). What made this occurrence unusual was, not only the circumstances of the nocturnal deaths, but the fact that the victims were young men, previously in good health. Reports of these cases increased over the following six years; a mortality rate of 92/100,000 showed these Hmong men were dying at a rate equivalent to the leading five

causes of death for American-born men of the same age range (Munger, 1987). CDC researchers noted that non-traumatic sudden death among previously healthy young men with no definitive underlying cause was rare (Centers for Disease Control, 1981). Furthermore, the shared features of the victims, including time of death, signs of respiratory distress preceding death, ethnicity, young age, and rapid transition from apparent health to death, suggested a distinct syndrome; this was subsequently termed “Sudden Unexpected Nocturnal Death Syndrome” (SUNDS) (Holtan, Carlson, Egbert, Mielke, & Thao, 1984).

Family interviews, case investigations, and small case–control studies, (Baron & Kirschner, 1983; Baron et al., 1983; Kirschner, Eckner, & Baron, 1986; Munger, 1987; Tatsanavivat et al., 1992) revealed no promising candidate risk factors. Post mortem exams revealed no evidence of prior pathophysiology, but suggested that the immediate cause of death was ventricular fibrillation leading to cardiac arrest (Munger, 1987; Munger et al., 1991; Otto et al., 1984). Based on reports of family members and those who attempted

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rescue, the fatal episode is now commonly summarized as having onset during sleep, with clear signs of agonal respiration, with including shallow, irregular breathing interrupted by pauses, choking, gasping, and otherwise labored respiration. The victims appeared to be unconscious and did not respond to attempts to awaken them (Holtan et al., 1984; Munger, 1987; Verrier & Josephson, 2011). Victims who were revived reported sensations of airway obstruction, chest discomfort or pressure, and weak or numb limbs (Verrier & Josephson, 2011).

Since the identification of SUNDS three decades ago, etiological research has been sparse and few hypotheses have been tested. Independent of a focus on SUNDS, in 1992 cardiovascular researchers identified Brugada syndrome, a cardiac abnormality characterized by a distinct ECG pattern and irregular heart rhythm (Brugada & Brugada, 1992). The syndrome is associated with sudden death, with most deaths occurring during the night, (Matsuo et al., 1999) and has been linked to genetic mutations, primarily of the SCNSA gene (Rook et al., 1999). Analyses of several large data bases of genotyped Brugada patients and healthy controls revealed mutation in SCNSA in approximately 21% of Brugada patients compared with 2–5% in healthy controls, supporting a genetic basis for this sudden cardiac death syndrome (Kapplinger et al., 2010). In a study of SCNSA gene mutations in 10 surviving SUNDS patients and their families, the mutation was found in 3 families (Vatta, Dumaine, Varghese et al., 2002). The authors concluded that SUNDS and Brugada syndrome were phenotypically, genetically and functionally the same disorder. Similarities to other conditions of sudden death in otherwise healthy persons indicate that Brugada syndrome may encompass other disorders such as Sudden Infant Death in addition to SUNDS (Fowler & Priori, 2009).

As is true of many other potentially fatal genetic disorders, not all those with the Brugada gene mutation suffer from its expression. Other exposures or triggers appear necessary to initiate the genetic–pathophysiologic mechanism. Recently, the role of sleep apnea and other sleep abnormalities in triggering the unique irregular heart rhythm of Brugada Syndrome has gained support as a possible etiological mechanism (Gami & Somers, 2008; Macedo et al., 2011; Verrier & Josephson, 2009).

Sleep apnea is characterized by repeated episodes of momentary airway closures (apnea, complete closure and pause in breathing; hypopnea, partial closure) as a result of reduced airway tone and collapse during sleep. The resulting breathing pauses have acute effects of hypoxia and cardiopulmonary instabilities and cause brief arousals to the wake state, which resumes airway tone but results in disrupted sleep patterns (Henry, 2013). In their overnight polysomnography study of 20 Brugada patients and 11 healthy controls, Macedo et al. (2011) found a 2-fold higher prevalence of sleep apnea in the Brugada patients (63%) compared to controls (27%). The authors concluded that the higher incidence of nocturnal death in patients with Brugada syndrome may be a result of co-morbidity with sleep apnea, whereby the apneic events and instability of sleep states associated with transitions between REM and non-REM sleep exacerbate significant cardiac rhythm abnormalities, (Macedo et al., 2011). Thus, some type of adverse sleep-related trigger interacting with a genetic susceptibility to fatal cardiac arrhythmias (i.e., Brugada syndrome) may explain SUNDS etiology.

*Dab tsog, sleep paralysis, and other sleep disorder symptoms: prevalent conditions in Hmong as well as SUNDS triggers?*

In contrast to the novelty of SUNDS to Western science in 1981, Hmong and other South–East Asian populations have long feared the personal experience epitomized by SUNDS. Culture-specific names have been given to this experience; Hmong refer to the terrifying nighttime occurrence of the crushing spirit on their chest

as dab tsog (Adler, 1995; Bliatout, 1982; Fukuda, Miyasity, Inugami, & Ishihara, 1987; Holtan et al., 1984). Victims of visits from this spirit report that dab tsog sat on their chest with crushing force, making it impossible to move and “took their breath”. Although parallels are drawn between SUNDS and the dab tsog experience, the high fatality of the medical syndrome of SUNDS differs from that of dab tsog: historical and ethnographic reports indicate that the experience of dab tsog is not rare or fatal, and is often experienced repeatedly by the victims (Adler, 1995, 2011). Thus, the cultural pattern, collective knowledge and universal description of dab tsog suggest a prevalent bio–psychosocial condition of which only a limited number of cases results in a SUNDS fatality. In a study of 118 Hmong in California, 58% reported at least one experience of the dab tsog visit; in-depth interviews clearly indicated widespread fear, stress, and dread of sleep abnormalities in the Hmong population (Adler, 1994).

The physical experience of both SUNDS survivors and victims of dab tsog is strongly suggestive of several sleep disorder symptoms, including sleep apnea, sleep paralysis, hypnogogic hallucinations and nightmares. Sleep paralysis is caused by the intrusion of wakefulness during a period of Rapid Eye Movement (REM) sleep during which the skeletal muscles are paralyzed (American Academy of Sleep Medicine, 2005, pp. 148–170). During this terrifying event, consciousness is retained, but the ability to speak or activate any voluntary muscle activity (such as moving the limbs or head) is absent (American Academy of Sleep Medicine, 2005, pp. 148–170).

Biomedical research has tended to focus on acute physiological mechanisms as the underlying cause of death by SUNDS. However, considering the wealth of historical and ethnographic reports which demonstrate widespread knowledge and experience of dab tsog that closely parallel sleep paralysis, sleep apnea, and other sleep disorders, it is clear that the cultural context of SUNDS is critical to inform the larger picture of the health and psychosocial burden of severe sleep problems and related stress in Hmong.

Sleep disorders may be triggers for SUNDS, but more importantly, may be under-recognized, highly significant Hmong health issues. Interviews of several Hmong communities indicate that a high proportion of Hmong, apart from SUNDS survivors, report sleep episodes characterized by pressure on their chest and the restricted ability to breath, indicating the possibility of breathing pauses of sleep apnea and REM-like disorders such as sleep paralysis, hallucinations, and/or severe nightmares (Adler, 2011).

Additionally, terrifying encounters with nocturnal spirits, whether as part of the traditional belief structure or exacerbated by conflict or loss of that structure (e.g., due to culture dislocation as part of the refugee experience) have been hypothesized as causes of severe psychological stress that may act as a trigger for SUNDS (Adler, 1994, 1995, 2011; Bliatout, 1982; Holtan et al., 1984).

However, regardless of whether severe or unique sleep disorders increase the risk of SUNDS, Hmong clearly, by their historical report, suffer from terrifying sleep experiences. If culture specific sleep terror (i.e., dab tsog), REM related disorders, and sleep apnea, are highly prevalent among Hmong, this would significantly increase Hmong general morbidity and mortality risk (including hypertension, stroke, depression, diminished quality of life), beyond any possible SUNDS risk (American Academy of Sleep Medicine, 2005, pp. 148–170; Institute of Medicine, 2006).

At present, the prevalence of sleep disorders in Hmong is unknown. There are no systematically collected sleep disorders data on a population sample of Hmong to determine whether this ethnic group, compared to the US population in general, is indeed at higher risk of sleep disorders. Furthermore, data on the relationship of cultural beliefs and culture-related stress with these sleep disorders is sparse. As a first step in understanding the

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