Chapter 6 Sleep and Sleep Deprivation Among Families in the ICU



Stuti J. Jaiswal and Robert L. Owens

Overview of Sleep: Background and Definitions

Sleep is the transient state in which all people spend 25–33% of their lifetimes. Its role in human health and disease is still poorly understood. However, it is increasingly recognized that sleep and sleep disorders have major impact on cardiovascular and neurocognitive health. For example, reported chronic short sleep duration – adjusted for all known covariates – is an independent risk factor for incident coronary artery disease [1], pneumonia [2], and weight gain [3]. Short sleep duration is associated with decreased antibody response to vaccination, suggesting immune modulation with short sleep [4, 5]. Recent epidemiological, basic, and animal research has begun to examine links between sleep duration and cancer [6]. Thus, sleep is likely to be important, but we have much to learn. Most society guidelines recommend 7–9 h of sleep per night [7, 8].

Sleep Stages

Sleep is typically divided into different sleep stages, based upon electroencephalographic (EEG), electrooculographic, and electromyographic patterns. The major division of sleep stages is between rapid eye movement (REM) and non-rapid eye movement (NREM) sleep. REM sleep shows characteristic conjugate eye

S. J. Jaiswal

The Scripps Research Institute, La Jolla, CA, USA e-mail: Jaiswal.Stuti@scrippshealth.org

R. L. Owens (⊠) Pulmonary, Critical Care and Sleep Medicine Division, University of California San Diego, La Jolla, CA, USA e-mail: rowens@ucsd.edu

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Fig. 6.1 An overnight hypnogram from a healthy subject that shows the pattern of the various sleep stages. The relative amounts of the sleep stages change with age, medications, and other factors

movements and is also referred to as "dreaming" sleep, as most recalled dreaming activity takes place during this phase of sleep. NREM sleep is further classified into phases called N1, N2, and N3 sleep, based upon the EEG appearance and rhythms (e.g., alpha, delta) that predominate. Because N3 is classified by delta wave activity (high amplitude, relatively slow frequency), it is sometimes referred to as slow wave sleep. In lay literature, either N3 or REM sleep is considered "deep" or "quality" sleep; however, the data to support these statements are incomplete. Although many studies consider the impact of sleep duration on a variety of outcomes (as above), the difficulty in reliably measuring the various sleep stages has limited the amount of studies that look at the various sleep stages and outcomes. Thus, most of the literature and this review will focus on overall sleep duration rather than specific sleep stages.

Typically, the sleep phases change throughout the night in a cyclical pattern of N1, N2, N3, then REM, and repeat (see normal hypnogram, Fig. 6.1, below) with a period of approximately 120 min. However, the timing and amounts of sleep can vary considerably according to multiple factors, including age, medication use, and genetics. For example, the amount of N3 sleep decreases with age. Alternatively, many commonly prescribed medications impact sleep stages, such as selective serotonin reuptake inhibitors (SSRIs) which suppress REM sleep, as well as most of the medications used in the ICU [9].

Circadian Rhythm

One of the most important factors affecting the timing of sleep in general and its various phases is the endogenous circadian rhythm. The circadian rhythm typically has a period of close to 24 h, with most rhythms also aligned for sleep during the



Fig. 6.2 The two stimuli for sleep are the endogenous circadian rhythm and sleep debt which accumulates during wake and recedes during sleep. Sleep during the night and with an early afternoon nap would mimic the endogenous circadian rhythm in most people

hours, 10 pm–6 am (and sometimes in the early afternoon; see Fig. 6.2). The endogenous circadian rhythm is affected by a variety of external cues, with light the most powerful. There is also variability in both the period and alignment. For example, some individuals show either an advanced or delayed sleep phase, with marked preference for either early morning (so-called morning larks) or late evening ("night owls"), respectively. However, when unable to accommodate to their preferred internal rhythm, symptoms of fatigue and sleepiness can result. The same mismatch between the internal circadian rhythm and the external environment commonly results in symptoms of "jet lag."

"I Can't Sleep": Lack of Opportunities for Sleep vs. Insomnia

Relevant to the ICU, family members of ICU patients often report difficulty sleeping. Broadly, this may be due either to lack of opportunities for sleep or insomnia, which have very different causes and treatments. Insomnia is defined as difficulty falling asleep, staying asleep, or non-restorative sleep *despite* an adequate opportunity for sleep. In the ICU, stress, anxiety, or other emotions could easily prevent sleep in a family member. However, the complaint of "I can't sleep" might more likely derive from the inability to find the right conditions for sleep in the ICU and could be due to light, sound, frequent interruptions, or lack of a bed/chair in which to sleep. These are both considered below.

Lack of Opportunities for Sleep: "I Don't Have Enough (Time, Space, Quiet) to Get Some Sleep"

Sleep is notoriously bad in the ICU, for both patients and their family members due to multiple reasons, with most pointing to environmental factors and frequent care interactions [10]. The primary rationale of the ICU is to group the sickest patients to allow for rapid responses as needed. This comes into direct conflict with efforts to promote sleep. Patients themselves will have unique barriers to sleep, such as pain, dyspnea, and ventilator dyssynchrony. However, loud alarms from multiple different types of equipment (e.g., telemetry, ventilator alarms), frequent interactions with clinicians, and procedures will interfere with sleep for both patients *and their loved ones*. Multiple studies have found the ICU to be a very poor environment for sleep, with very high sound levels, for example, frequently exceeding WHO-recommended guidelines [11, 12]. Thus, the Society of Critical Care Medicine recommends promotion of the sleep environment by clustering routines, optimizing the environment for sleep, and promoting uninterrupted sleep times [13].

Efforts to improve the sleep environment in the ICU have been difficult. Multiple interventions, which require substantial staff education and changes in practice, may be required [14]. Even in the landmark study by Kamdar and colleagues designed to improve sleep quality, which demonstrated an important reduction in ICU delirium, no improvement in patient subjective sleep quality was found. While multimodal interventions are unlikely to be implemented easily, even more targeted interventions must be carefully considered. For example, "just" focusing on noise reduction can result in statistically significant changes in noise level, but these are small and unlikely to have clinical benefit. Moreover, efforts to reduce noise levels may paradoxically increase difficulty sleeping since it is changes in sound level that actually lead to arousal from sleep [15, 16]. Consider the use of white noise machines to aid sleep, which work in part by increasing the average background noise level. Earplugs and eye masks have been shown to modestly improve sleep (increasing sleep time by about 16 min per night) for healthy patients exposed to a simulated ICU environment [17]; however, comfort and acceptance of earplugs in particular is low [18]. Finally, while efforts to reduce light during the circadian night are frequently recommended, light levels, when measured, have been low at night [19]. Instead, more light may be needed during the day to maintain a circadian rhythm, a finding seen in multiple studies [16, 19, 20].

Family members must encounter all of these problems and also frequently face additional challenges. First, some ICUs lack a physical space for family members to sleep or that space is a communal waiting room which is not designed for sleep or privacy. Second, family members may have multiple other interruptions not related to the ICU environment such as updating other family members, other work obligations, etc. Third, family members may also travel from distance and deal with the effects of jet lag as well. Finally, stress and anxiety may cause insomnia, preventing sleep even when the ICU environment allows it. Indeed, family members themselves report anxiety, tension, and fearfulness as the three most common causes of sleep disturbance, much more commonly than environmental factors such as unfamiliar bed or too much noise [21]. Stress may not only be about the medical condition of their loved one, but family members can also face financial stress in the form of substantial nonmedical out-of-pocket expenses such as meals, lodging, and parking or from missed days at work [22].

How Well Do Family Members Sleep in the Hospital?

Emerging literature suggest that family members of critically ill patients are sleep deprived and that they have symptoms as a result, although the symptoms vary between individuals [23]. There are few studies that have objectively measured sleep times of family members in the ICU. In this regard, the work by Choi and colleagues, while based on a limited sample, is an important first step. Using actigraphy, they found that family members of ICU patients at the time of ICU admission averaged $328 \pm 71 \text{ min}$ (i.e., <5.5 h) of sleep per night [24]. Family members of ICU patients often report fatigue and difficultly sleeping [25]. Family members report inadequate rest, and nearly half report an inability to slow down or rest when *they themselves* are sick [27]. This follows a general pattern where family members prioritize presence in the ICU rather than their own health, missing doctor's appointments of their own, missing scheduled medications, skipping meals, etc.

Why Do Family Members Put Themselves Through These Conditions?

Multiple studies have shown that family members want to stay with patients for a variety of reasons. Primarily, most report a desire to safeguard and support their loved ones [28, 29]. But open visitation is also associated with improved family satisfaction [30, 31] and reduced family anxiety [32] and has the practical benefit of improved communication with clinicians [33]. Recognizing these benefits, guide-lines for family-centered care recommend open visitation and promote family presence [34]. However, increased family presence may worsen family and potentially patient sleep.

Could Family Presence Lead to Poor Patient Sleep?

Some families may visit loved ones according to their own schedule, such as late at night after work or during other designated rest times for patients. While no evidence exists that such visits should be discouraged, families should be educated on the importance of uninterrupted rest time [35]. Conversely, families should

understand that periods of wake and mobilization are equally important and that sedation and sleep are not the same. For example, some family members may interpret the deeply sedated patient as sleeping comfortably and discourage efforts to lighten sedation or perform interruptions of sedation, despite evidence that such efforts are beneficial [36]. Families may also defer opportunities for mobilization since their loved one is "sleeping," even though early mobilization may confer benefit [37]. Finally, some families may ask for pharmacological interventions, i.e., sleeping pills, to aid in sleep although risks usually outweigh any benefit [38].

Impact of Sleep Deprivation

There are very few studies carried out among ICU family members specifically. Thus, we extrapolate from the literature of acute sleep deprivation. One interesting study is by van Dongen and colleagues [39]. They exposed young healthy subjects to various degrees of sleep restriction/deprivation for up to 14 days. Each day, subjects rated their subjective sleepiness and also completed the psychomotor vigilance test (PVT), a test of alertness. Subjects restricted to only 4 or 6 h per day felt tired, but their subjective sleepiness plateaued after a few days. In contrast, the objective PVT showed continued worsening every day. *Thus, one of the features of sleep deprivation is the inability for people to recognize how affected they are by sleep deprivation.* Relevant for families of ICU patients, families may not appreciate the degree of sleep deprivation they are experiencing or the impact of that sleep deprivation.

In general, the following domains impacted by acute sleep deprivation are likely to be important for family members and their interaction with the healthcare team. Sleep deprivation can cause increases in lapses in attention, increased risk taking [40], irritability, and decreased trust in others and increased aggressiveness [41].

One of the few studies to specifically test cognition in ICU family members found that most showed lapses in attention as measured by the psychomotor vigilance test [26]. Additionally, in this study, those subjects who were subjectively sleepy also experienced greater impairment in performing daily activities.

Taken together, lack of sleep may impact how families interact with clinicians, how they interpret information, and how they make decisions that affect their loved ones. Adequate sleep could be an important part of building a therapeutic bond between family and clinicians [42], and the atmosphere of the ICU is a factor identified as important in predicting family member dissatisfaction with intensive care [43]. For family members themselves, lack of sleep may impact decisions about their own care, such as ability to drive while drowsy [44].

Management of Sleep Deprivation

In general, the treatment for sleep deprivation is adequate sleep, which could occur during the night or as naps throughout the day. Caffeine is also frequently used (by both providers and family members) to mitigate the impact of sleep deprivation. An important corollary is the avoidance of sedatives such as alcohol or sleeping pills (e.g., benzodiazepines) which cause increased sedation but are unlikely to be effective at promoting sleep unless the sleep environment is also improved.

Suggestions for Improving Family Sleep in the ICU

There are few data to suggest how best to improve family sleep. Until such data become available, the suggestions below are based on common sense. We emphasize that consideration of *both* patient and family member sleep might be useful, as has been suggested when assessing mental wellbeing of patient-caregiver dyads [45]. Finally, other efforts that are not sleep specific – such as improved education and communication with families that generally reduces anxiety – have been advocated and may also be useful [46]:

- Improved physical space for sleeping. This has been suggested as part of recent guidelines. Our own experience when physically relocating our ICU to new facilities (same type of patients, same providers, and same care policies in both ICUs) was an increase in nighttime visits by family members. While sleep and effects of sleep deprivation were not directly assessed, the average number of visitors in patient rooms at night increased from 50% of patients to 79% of patients [47]. In this regard, neonatal ICUs can lead the way, with sleeping areas for parents that allow closeness with their child and, at times, privacy [48].
- 2. Education for families about the importance of wake and sleep. As above, information to educate and engage family members will be important. Interestingly, some patients, and family members, feel secure with abundant nighttime activity and alarms [10]. What many clinicians and some patients/family members interpret as barriers to sleep are interpreted as active monitoring by others. Thus, any intervention will need some element of education for patient and families to provide reassurance. With appropriate education, family members may be the biggest advocates for uninterrupted rest time as well as periods of activity during the day. Furthermore, this information might also include education and resources about sleep after the ICU for both patients and family members.



Fig. 6.3 Example protocol to optimize sleep in the hospital for both patients and family members. Activities during the day would ideally include family members. Bedtime tuck in would be aimed at patients and family members

- 3. Active management of family member wake and sleep time. Family member sleep could be encouraged both during the night and during rest ("nap") times during the day. Not only would such management improve family member sleep, but it may also improve patient sleep as well. For example, empowering family members to act as guardians of sleep time may also help reduce nighttime interruptions. During active periods during the day, family members might be encouraged to increase light levels in the room (which are frequently too low to entrain the circadian rhythm) [16, 19] and engage family members in conversations or simple cognitive activities (e.g., card playing) that might be useful in preventing or reducing delirium [49]. Similarly, if physically able and with appropriate guidance, they might participate in range-of-motion or other activities. This role for family members might provide a sense of usefulness for them and foster teamwork with the clinical team. See Fig. 6.3. We note that family engagement is now considered in the design of clinical trials [50]. Importantly, such physical activity during the day could improve family member's insomnia [51–53].
- 4. Create protected sleep times at night and during the day for both patient and family. We have previously advocated for a "tuck-in" time which would signal the start of the nighttime rest period for the patient [54]. For patients this might include management of pain and comfort, preparation of the room for sleep (lights down, TV off, setting of optimal desired temperature, etc.), and offering of earplugs and eye masks. Importantly, the "tuck in" could also be extended to family, as well, who could also be offered eye masks and earplugs. Family members could also be encouraged to disengage from their mobile phone and other electronic devices.

Insomnia: "I Just Can't Seem to (Fall, Stay) Asleep"

A separate problem is insomnia – the inability to fall asleep despite an adequate opportunity to do so. Thus, lack of an opportunity for sleep may occur mostly when families attempt to sleep in the ICU, and insomnia might occur outside of the ICU. Insomnia is one of the most common medical conditions, and some studies suggest that almost all Americans will have an episode of acute insomnia at some point during their lifetime. Insomnia can include difficulty falling asleep, staying asleep, or waking up too early with inability to fall back asleep. This difficulty sleeping must also be paired with symptoms or distress from the poor sleep. Insomnia is endorsed frequently by ICU family members, and symptoms frequently correlate with stress or anxiety [21, 55, 56].

While insomnia may be a reflection of stress or anxiety, it may persist and become the dominant symptom even after the initial stress/anxiety has resolved. For example, stress over a loved one's admission to the ICU may be the inciting event for prolonged insomnia even in family members of patients who recover well from critical illness. People with insomnia frequently have anxiety and frustration about their difficulty sleeping, and their responses to insomnia can further prolong or worsen sleep difficulties. People with difficulty falling asleep may perseverate on the problem by watching the clock or feel frustrated lying in bed awake. They may also compensate by staying in bed longer the next morning. All these behaviors will make it difficult to fall asleep the next night as well. Effective therapy focuses on eliminating the vicious cycle of these behaviors.

The cornerstone of therapy for insomnia is non-pharmacological. Education and cognitive behavioral therapy are the best initial treatment options. Education focuses on so-called sleep "hygiene" – the behaviors that help promote sleep, such as avoidance of naps (note that this is an effective strategy for sleep deprivation but will worsen insomnia) and maintenance of a consistent sleep schedule. Avoidance of behaviors that promote frustration with sleep, such as avoidance of clock watching or staying in bed awake, is recommended (i.e., stimulus control). For some, sleep restriction – the avoidance of too much time in bed – can also be very helpful. Medication would only be considered after an evaluation by a physician.

Sleep after the ICU

Both sleep deprivation and insomnia can occur after the ICU, depending on the course of illness for the patient. For those whose loved ones died in the ICU, the major post-ICU sleep abnormality may be insomnia in the setting of grief or subsequent depression. Conversely, those whose family members survive the ICU and

return home may experience both insomnia and sleep deprivation as a result of the care they must provide to their loved ones. Multiple studies have shown that caregiver burden can be quite high and remain high after the ICU, particularly at the time of discharge home [57–62]. The course of caregiver burden is variable [63], and there are few data. As a starting point, in the study by Choi and colleagues, actigraphy was extended up to 2 months after the ICU [24]. We note that total sleep time at 2 months was highest in those whose family members died in the ICU, but their sleep tended to be more fragmented with more wake after sleep onset, a marker of insomnia. Conversely, those who family members returned home got less sleep, which was less fragmented. Thus, sleep is likely to be poor in caregivers after ICU discharge for a variety of reasons and will fluctuate over time. (See Fig. 6.4 conceptual examples.)



Fig. 6.4 Difficulty sleeping can be explained by lack of adequate sleep opportunity, insomnia, or both. The relative contribution of each may also fluctuate during the hospital stay and based on the outcome of the ICU patient. In panel (**a**), the patient survives to eventual home discharge. There may be a "honeymoon period" when caregivers sleep well, as patients improve yet remain cared for by others. This period may end when the patient returns home and caregiver burden increases or as anxiety builds over the slow pace of recovery. In panel (**b**), the patient does not survive to ICU discharge

In order to improve sleep after the ICU, it will be important first to obtain sufficient history to understand why the family member "can't sleep." Education to family members about the signs and symptoms of insomnia and basic sleep hygiene tips may be helpful. Persistent insomnia should prompt evaluation by a physician, and medication should be considered a last resort. If poor sleep is due to high caregiver burden, some caregiver relief will be needed.

Sleep and Relationship with PICS-F

Anxiety, depression, and posttraumatic stress disorder (PTSD) are now recognized complications for family members of ICU patients, and this constellation of symptoms has been termed post-ICU care syndrome-family (PICS-F) [64]. Poor sleep, then, may be a prominent symptom of PICS-F. Whether poor sleep in the hospital predisposes to PICS-F is not clear. Interestingly, some studies have shown that sleep deprivation after trauma reduces subsequent anxiety and development of PTSD [65–67]. It has been hypothesized that sleep deprivation slows or prevents new memory formation that could be used to reexperience the trauma.

Regardless of any possible causal role, an emphasis on improving sleep and reducing insomnia may improve symptoms of anxiety or depression [68]. Alternatively, sleep symptoms in PTSD are often particularly refractory and may need a focused approach [69]. Thus, a sleep history and a focus on sleep/difficulty sleeping will be important in family members after the ICU.

Summary

Difficulty in sleeping is a problem not only for patients in the ICU but also for their family members. Insufficient sleep causes symptoms in family members and may affect relationships with clinicians. An important first step is to differentiate between lack of opportunities for sleep vs. insomnia. Efforts to improve sleep for family members might also improve sleep for patients as well. Family members should be educated about symptoms of insomnia and first-step strategies to manage it.

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