Approaches to Measure Sleep–Wake Disturbances in Adolescents With Cancer

Jeanne M. Erickson, MSN, RN, AOCN

Sleep–wake disturbances commonly occur in healthy adolescents. Although diminished sleep and sleepiness seem normal for healthy adolescents, adolescents with chronic illnesses face additional disruption in the quantity and quality of their sleep as a result of the disease process, ongoing treatment, and associated symptoms. Little is known about how sleep in adolescents is affected by cancer, cancer treatment, and concurrent symptoms or about the consequences of sleep disruption for these patients. Although there is limited evidence to guide sleep measurement in adolescents with cancer, researchers may learn effective strategies from sleep studies completed with adolescents with other conditions. This systematic review examines how researchers have measured sleep using actigraphy, diary, and/or self-report questionnaires in diverse samples of healthy and ill adolescents. Psychometric properties are reported for nine self-report sleep questionnaires that were used in studies with mostly healthy adolescent samples. Nineteen studies provide evidence that actigraphy can be successfully and reliably used as an effective objective method to measure sleep in adolescents, including those with chronic illness. Daily sleep diaries were used less frequently to collect data from adolescents. The suitability of these techniques for the study of cancer-related sleep–wake disturbances in adolescents as well as strategies to enhance the reliability, validity, and feasibility of these measures will be discussed. Future sleep research in adolescents affected by cancer can be strengthened by the consistent use of sleep terminology, measurement of key sleep parameters, and efforts to develop and use psychometrically sound instruments. Oncology clinicians should be ready to add emerging evidence from sleep research to their care of adolescents with cancer.

Key words: Adolescents; Cancer; Sleep

THE PROBLEMS OF insufficient sleep and daytime sleepiness are critical problems for American adolescents. These sleep–wake disturbances result as several unique physiological, psychosocial, and behavioral factors converge during this developmental stage. Research has shown that an internal sleep phase delay toward later bedtimes and increased daytime sleepiness are normal changes that occur during adolescence (Millman, 2005). In addition, teenagers get less sleep as they assume greater independence from parents, take on increasing work and academic demands, and participate in social activities with peers. The consequences of insufficient sleep and daytime sleepiness include such significant negative outcomes as increased automobile accidents, increased substance abuse, decreased academic performance, and decreased mood (National Sleep Foundation, 2000). Thus, efforts to focus on and improve sleep for adolescents are necessary for their health, safety, and well-being.

Although diminished sleep and sleepiness seem normal for healthy adolescents, adolescents with chronic illnesses face additional disruption in the quantity and quality of their sleep as a result of the disease process, ongoing treatment, and associated symptoms. Excluding specific sleep disorders, research shows that adolescents diagnosed with HIV (Franck et al., 1999), chronic pain (Meltzer, Logan, & Mindell, 2005; Palermo & Kiska, 2005), diabetes (Happe, Treptau, Ziegler, & Harms, 2005), renal disease (Davis, Baron, O'Riodan, & Rosen, 2005), epilepsy (Magnanti et al., 2006), depression (Bertocci et al., 2005), and cancer (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; Hinds, Hockenberry, Gattuso, et al., 2007; Hinds, Hockenberry, Rai, et al., 2007) report a variety of sleep–wake disturbances, especially an increased number of nighttime awakenings, difficulty falling asleep, and excessive daytime sleepiness.

From the University of Utah College of Nursing, Salt Lake City, UT; University of Virginia School of Nursing, Charlottesville, VA.
Corresponding author: Jeanne M. Erickson, MSN, RN, AOCN. E-mail: jme3a@virginia.edu
0882-5963/$-see front matter

doi:10.1016/j.pedn.2008.03.004

One of the challenges in sleep research with adolescents is selecting a valid and reliable method to measure sleep that is feasible with this age-group. A number of objective and subjective techniques for sleep measurement have been used to explore the sleep–wake disturbances in adults, but some instruments may not be suitable for research with adolescents. Likewise, many pediatric measures use parent-proxy report, which is not consistently reliable with adolescents (Dashiff, 2001; Hinds, Hockenberry, Gattuso, et al., 2007). Extensive sleep research has been completed with healthy adolescents using a variety of approaches, and information from these studies may help guide the investigator's choice of a sleep measurement approach for adolescents with cancer. This article provides an overview of the unique aspects of sleep in adolescents and introduces variables recommended for sleep measurement in oncology populations. The purpose of this article is to identify sleep studies where actigraphy, self-report questionnaires, and diaries have been used to measure sleep in adolescents. The applicability and feasibility of using these instruments for sleep research with adolescents with cancer will be discussed as well as strategies and recommendations for optimal sleep data collection.

SLEEP PHYSIOLOGY

Sleep is a behavioral state of disengagement and unresponsiveness to the environment that is associated with physiological processes vital to life (Carskadon & Dement, 2005). Although the functions of sleep remain challenging to define, various theories suggest that sleep is an active state important for energy conservation, brain function, and learning. More recent propositions link sleep to the regulation of metabolism, hormone production, and immune function critical for good health and disease prevention (Bonnet, 2005).

It is well established that the sleep–wake cycle in humans follows a diurnal circadian rhythm of approximately 24 hours (Turek, Dugovic, & Laposky, 2005). Sleep alternates with a state of wakefulness, characterized by readiness of the brain to respond to outside stimuli. Periods of sleep are divided into two general categories: rapid eye movement (REM) sleep and non-REM sleep. Non-REM sleep is further divided into four stages, which vary from light sleep (Stage I) to deep sleep (Stage IV). Non-REM sleep is normally associated with minimal brain activity and a moderate amount of body activity, whereas REM sleep includes bursts of rapid brain waves associated with dreaming and muscle atonia interrupted with episodes of muscle twitching. A typical night of sleep begins with the onset of sleep in Stage I, followed by several alternating cycles of various stages of non-REM and REM sleep, which average 90 to 110 minutes in length (Carskadon & Dement, 2005). Early episodes of REM sleep are short but become longer as the night progresses. Age, sleep history, circadian rhythms, and temperature are some factors that influence length of sleep and sleep stages. Detailed physiologic measurements during sleep have led to established norms for patterns, durations, and timing of various sleep stages and cycles, which change with age (Lashley, 2004).

The two-process model of sleep regulation, initially developed by Borbely in 1982 and since refined by others, proposes that individual sleep and wake times are determined by the interaction of a circadian timing system and a sleep–wake homeostasis process, each controlled by separate mechanisms (Carskadon, Acebo, & Jenni, 2004). The circadian timing system is controlled by an internal "clock," located in the suprachiasmatic nucleus (SCN) in the anterior hypothalamus. The SCN synchronizes an elaborate feedback loop of neuronal activity and release of neuropeptides, involving multiple oscillators located in tissues throughout the body. Although the circadian system is self-sustained, it incorporates stimuli from the environment, especially related to the light–dark cycle. The second process, sleep–wake homeostasis, is influenced by the individual's sleep–wake behaviors and depends upon the duration and quality of prior episodes of wakefulness and sleep. Homeostatic sleep propensity, or the drive to sleep, rises during waking hours and peaks just prior to bedtime, followed by dissipation during sleep with a nadir at the morning wake time. The sleep–wake cycle interacts with the circadian clock in the central nervous system, and when the two regulatory processes are ideally coordinated, outcomes include optimal wake-time performance and sleep consolidation (Dijk & Franken, 2005). Minor changes in either process can influence the timing of sleep and wakefulness as well as the duration and structure of sleep, such as those which occur during normal aging or as a result of lifestyle behaviors, including rotating shift work and travel across time zones.

Sleep in Adolescents

In 1997, the National Institutes of Health called attention to the sleep problems of adolescents and summarized existing sleep research with