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Approaches to Measure Sleep-Wake Disturbances in Adolescents with Cancer

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Abstract

Sleep-wake disturbances commonly occur in healthy adolescents. While 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.

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,

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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.

While 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 human immunodeficiency virus (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 (Maganti et al., 2006), depression (Bertocci et al., 2005), and cancer (Gedaly-Duff et al, 2006; Hinds et al, 2007a, 2007b) report a variety of sleep-wake disturbances, especially an increased number of nighttime awakenings, difficulty falling asleep, and excessive daytime sleepiness.

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 (Hinds et al., 2007a; Dashiff, 2001). 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 paper provides an overview of the unique aspects of sleep in adolescents and introduces variables recommended for sleep measurement in oncology populations. The purpose of the paper 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 and 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). While 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, while 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 90-110 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, 2003).

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. While 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 adolescents in their Research Report, “Adolescent Sleep Needs and Patterns” (National Sleep Foundation, 2000). Adolescents show a marked decrease in the amount of REM sleep, REM density, and changes in REM patterns. Adolescent sleep also evidences less deep sleep in stages III and IV. It is possible that as a result of these changes, even when their nighttime sleep is optimal at the recommended nine hours per night, adolescents complain of increased daytime sleepiness and demonstrate an increased tendency to fall asleep during the day (Carskadon, Vieri, & Acebo, 1993; Carskadon, Wolfson, Acebo, Tzischinsky, & Seifer, 1998). Adolescents also appear to develop a phase delay in their circadian cycle toward a cycle that exceeds 24 hours, resulting in a shift toward later bedtimes (Wolfson & Carskadon, 1998).

At the same time as these biological changes alter adolescents' circadian cycle and stages of sleep, changes in their lifestyle behaviors also lead to fewer sleep hours. Their schedules expand to include more time spent in school, sports, hobbies, and employment, as well as social time with friends. They have greater independence to choose their own activities and set later bedtimes, often choosing to stay up later for extra socializing or entertainment through television or the Internet. Survey data show that while adolescents need 8.5 to 9.25 hours of sleep each night, they average less than 8 hours per night during the school week (Millman, 2005). When they get up for early school start times, teenagers accumulate significant sleep debt during the school week and compensate for lost hours of sleep by extending sleep on weekends, contributing to irregular sleep schedules. This cycle of discrepant sleep schedules can perpetuate problems of disrupted and fragmented sleep (Millman).

These internal and external changes in adolescent sleep patterns lead to problems related to insufficient sleep, increased daytime sleepiness, and complaints of fatigue. These problems, in turn, are associated with a variety of negative safety, health, and performance outcomes. Drowsiness, fatigue, and lapses in attention are identified as contributing factors in teenage automobile crashes and as well as other non-traffic injuries, such as employment accidents (National Sleep Foundation, 2000). Study findings report shorter sleep times and irregular sleep

schedules are associated with poor school performance in adolescents (Wolfson et al., 2003). In contrast, students who report better quality sleep and feeling more rested also report higher motivation and confidence to do well in school (Fredriksen, Rhodes, Reddy, & Way, 2004). Research findings have also associated insufficient sleep with mood disturbances, including depression, emotional lability, and inability to concentrate (Carskadon, Acebo, & Jenni, 2004; Wolfson & Carskadon, 1998).

Sleep in Adolescents with Cancer

For adolescents with cancer, there is evidence from symptom management studies that adolescents report disturbed sleep during cancer treatment. In qualitative studies exploring cancer-related fatigue, adolescents cited sleep variables as contributing factors to fatigue (Hockenberry-Eaton et al., 1998; Davies et al., 2002). These variables included changes in sleep patterns, sleep positions, and environmental disturbances in the hospital setting. Patients undergoing stem cell transplantation reported increased sleep disturbances during the first three weeks of treatment which decreased after discharge from the hospital (Phipps, Dunavant, Garvie, Lensing, & Rai, 2002). Two pediatric oncology studies specifically focused on sleep in children and adolescents with cancer. Gedaly-Duff and colleagues (2006) found that during the maintenance phase of ALL, patients experienced decreased total sleep time and more frequent awakenings. They suggested that pain may contribute to more fragmented sleep and lead to increased fatigue. Hinds et al. (2007b) found that treatment with steroids contributed to increased sleep time and fatigue in patients with acute lymphoblastic leukemia (ALL). Another recent study with hospitalized children and adolescents with cancer explored the relationship between sleep quality and fatigue. Patients who experienced more sleep interruptions and nocturnal awakenings had longer sleep periods and reported more fatigue (Hinds et al., 2007a). However, more research is needed to build upon this emerging body of knowledge about sleep disturbances in adolescents with cancer, which is limited by small sample sizes, samples that include younger children, and sleep measurement with a single item or question. Specifically, there is a need to address issues related to sleep measurement, potential contributing factors, and the effects of disrupted sleep on patient outcomes in adolescents with cancer. Sleep-promoting interventions specific to adolescents then need to be developed and tested with evidence introduced into clinical practice.

Sleep Measurement

To evaluate sleep-wake disturbances in adolescents with cancer, oncology caregivers need to consider which sleep variables to measure and how to measure them. A single item or question, such as, “Do you have difficulty sleeping?” or “How many hours of sleep do you usually get?” are not adequate to evaluate problems related to falling asleep, night-time awakenings, or trouble with daytime sleepiness. To guide oncology clinicians and researchers in sleep inquiry, a panel of oncology sleep researchers proposed measurement of nine sleep parameters to provide a comprehensive evaluation of sleep-wake disturbances (Berger et al, 2005). These sleep parameters are listed in Table 1.

Except for a subjective report of sleep quality, each variable can be measured using a subjective or objective approach. Subjective sleep measures include self-report questionnaires and daily sleep diaries or logs. Objective sleep measures include polysomnography, the gold standard, and actigraphy. Polysomnography is an assessment usually performed in an overnight sleep laboratory and includes neurological and neuromuscular measurements recorded by electroencephalogram (EEG), electrooculogram (EOG), and electromyelogram (EMG) as well as assessment of cardiac and respiratory parameters. Actigraphy is a second objective approach to sleep measurement using a movement-sensing and recording device, worn on the wrist or ankle. The device interprets patterns of movement in epochs of time as sleep or wake periods

using computer algorithms to translate data into numeric and graphic values. Although subjective and objective measures of sleep do not consistently correlate, each set of results yields useful information, and each measurement approach has a unique set of benefits and limitations (Lashley, 2004). Thus, a combination of sleep measures using subjective and objective approaches is often recommended (Gaina, Sekine, Chen, Hamanishi, & Kagamimori, 2004a; Sadeh, Raviv, & Gruber, 2000; Wolfson et al, 2003).

In an effort to advance sleep research in adolescents with cancer, this systematic review examined the literature for sleep measurement approaches that have been used with adolescents. Although polysomnography is the gold standard, this approach is expensive, requires the use of specialized equipment and trained technicians, and is usually reserved to answer questions related to sleep stages and other physiologic variables. Therefore, this review focuses on adolescent sleep studies that used actigraphy, self-report questionnaires, and sleep diaries – approaches that are more readily accessible and feasible for oncology clinicians and researchers. The research review includes information from sleep studies located in Medline and CINAHL databases that met the following criteria: 1) were published in English between 1998 and 2007; 2) had adolescent samples (mean age between 10 and 20 years); and 3) used actigraphy, diary, and/or self-report questionnaires that reported psychometric data. Questionnaires that were developed and reported by a single researcher without reports of psychometric data were not included in the review nor were questionnaires that used parent-proxy report or measured sleep with a single item. Studies that focused on sleep in adolescents with medically diagnosed sleep disorders, such as obstructive sleep apnea and restless leg syndrome, were also excluded in this review.

Results

This systematic review identified a number of studies that examined adolescent sleep using actigraphy, self-report questionnaires, and diaries using the inclusion criteria outlined above. These measurement approaches will be discussed along with considerations for their use with adolescent oncology patients.

Actigraphy

The search identified nineteen studies that used actigraphy to measure sleep in healthy adolescents as well as adolescents diagnosed with a variety of chronic illnesses. The aims of the studies were descriptive as well as intervention-testing. Two studies focused specifically on sleep in children and adolescents with cancer. Hinds et al. (2007b) measured sleep in 29 hospitalized patients receiving chemotherapy for a solid tumor or acute myeloid leukemia (AML), and Gedaly-Duff et al. (2006) measured sleep at home in nine patients with acute lymphocytic leukemia (ALL). The adolescents in these studies wore actigraphs for periods ranging from 2 to 14 days. In an accompanying sleep log or diary, adolescents typically recorded other data to assist with data analysis, such as daily bedtime, time out of bed, and times when the device was removed (Sadeh, Sharkey, & Carskadon, 1994). The studies reported a variety of sleep variables objectively measured by actigraphy, including total sleep time, sleep latency, number of awakenings, and wake time after sleep onset. Several different actigraph models were used in the studies, and scoring was completed with different software programs and mathematical algorithms. Table 2 includes information about the actigraphy studies with adolescents, along with comments about technical difficulties. Acebo and colleagues (1999) concluded that at least five nights of actigraphy recordings (either weekday-night or weekend-night) were required for adequate reliability estimates (greater than 0.70) of aggregated values. They also found that measures of sleep minutes and sleep period were the least reliable aggregated actigraphy variable. Sadeh and colleagues (2000) reported reliability estimates ranging from 0.66 to 0.91 for aggregated values calculated for a 5-day recording

period. Actigraph data have been shown to correlate with polysomnography recordings in infants, children, and adults, except in patients with highly disturbed sleep or movement disorders (Littner et al, 2003), confirming it as an accurate measurement approach. Johnson, Kirchner, Rosen, Storfer-Isser, Cartar et al. (2007) explored the reliability of actigraphy in a sample of 181 adolescents, comparing actigraphy data from three different modes of analysis to overnight polysomnography (PSG). They found that actigraphy underestimated sleep duration compared to PSG in these adolescent participants, with more accurate estimates of sleep duration in females.

Except for the subjects with autism, investigators reported over 90 % compliance with adolescents' use of actigraphs, confirming feasibility in healthy adolescents as well as those with acute and chronic illnesses. Technical problems resulted in loss of up to 20% of actigraph data, and other problems with actigraphs included broken straps, allergic reactions, and adolescents who forgot to replace the devices after swimming or bathing – problems similar to actigraphy use with adults. Benefits of actigraphy relate to its ability to objectively measure the subject's sleep by continuous recording over several days in a natural setting during normal activities. Drawbacks include the need for training in use of the actigraph and the accompanying computer software for data analysis. Use of actigraphy may also be limited to smaller samples because of practical issues related to expenses and availability of equipment.

Self-report sleep questionnaires

Self-report sleep questionnaires commonly ask participants to retrospectively report about their sleep for a specified period of time. In Table 3, nine self-report questionnaires are described that have been used in sleep studies with adolescents. These questionnaires include a variety of the sleep parameters and most commonly measure daytime sleepiness, quality of sleep, circadian rhythm tendencies, total sleep time, and sleep latency. Some instruments and subscales also ask about behaviors that facilitate or inhibit sleep, including the use of alcohol, tobacco, and sleep medications, as well as other sleep habits and sleep settings. The instruments have periods of recall that range from one week to ‘past months’ and use a variety of responses and scoring approaches.

Table 4 provides psychometric information about each sleep questionnaire that was reported in a sleep study or studies with adolescents. There is support for two scales to measure sleepiness in adolescents: the Epworth Sleepiness Scale (ESS) and the Pediatric Daytime Sleepiness Scale (PDSS). The ESS has also been used in several other large studies with healthy adolescents in Korea (Joo, Shin, Kim, Yi, Ahn Park, et al., 2005), Mexico (Moo-Estrella, Perez-Benitez, Solis-Rodriguez, & Arankowsky-Sandoval, 2005), Poland (Oginska & Pokorski, 2006), and the United States (US) (Pilcher, Schoeling, & Prosansky, 2000), although no psychometric data is reported. The PDSS has also been used to study sleepiness in overweight adolescents (Beebe, Lewin, Zeller, McCabe, MacLeod et al., 2007).

Several scales are available to measure sleep behaviors and sleep quality. In addition to the studies listed in the table, Carskadon's School Habits Survey (Carskadon et al., 1991) has been used in a number of large scale surveys with healthy adolescents in the US (Amschler & MacKenzie, 2005; Mercer, Merritt, & Cowell, 1998; O'Brien & Mindell, 2005; Owens, Stahl, Patton, Reddy, & Crouch, 2006; Stallones, Beseler, & Chen, 2006), Croatia (Radovic-Vadacek & Koscec, 2004), Korea (Yang, Kim, Patel, & Lee, 2005), and Italy (Russo, Bruni, Lucidi, Ferri, & Violani, 2007). The Survey has also been used to study adolescents with pain (Meltzer, Logan, Mindell, 2005; Palermo & Kiska, 2005). Sadeh's Sleep Questionnaire has been used to study sleep in Israeli adolescents with headache (Bursztein, Bernstein, & Sadeh, 2006). Gaina and colleagues have measured sleep in several large studies with healthy Japanese adolescents using their Sleep Questionnaire (Gaina, Sekine, Hamanishi, Chen, & Kagamimori, 2005;

Gaina, Sekine, Kanayama, Takashi, Hu, et al., 2006; Gaina, Sekine, Shimako, Ziaoli, Hitomi, et al., 2006).

In summary, none of the self-report sleep questionnaires used with adolescents addresses all nine parameters recommended by oncology sleep experts. Many of the self-report sleep questionnaires need more reliability and validity testing, and none have been used to study sleep in adolescents who have cancer. Although there is moderate support for the reliability and validity of Carskadon's School Habits Survey (Carskadon et al., 1991) and Gaina's Sleep Questionnaire (Gaina et al., 2004b), these measures have limitations for use with adolescent subjects who do not regularly attend school because items on both questionnaires ask specifically about sleep-wake patterns on school days. The School Sleep Habits Survey, for example, asks questions about the subject's sleep during the past two school weeks and about ‘usual’ sleep and wake times on school days. Gaina's Sleep Questionnaire includes categories for ‘school days’ and ‘weekends.’ Adolescents who have irregular school attendance, who are not currently in school, or who follow a flexible home-schooling routine would find these questions inapplicable or difficult to answer. Since psychometric data from the studies show these self-report measures are less valid when adolescents report sleep from less-structured non-school days, these instruments may be better suited for testing with adolescent cancer-survivors who are regularly attending school or work. Finally, other limitations of self-report sleep surveys include issues related to subject recall and bias. This is especially problematic in adolescents, who may provide the most socially desirable responses rather than the most accurate (Wolfson et al, 2003).

Sleep diary

Daily sleep diaries or logs are recommended for use with actigraphy to identify artifacts, bedtimes, and wake-times and support data analysis (Littner et al., 2003). Daily sleep diaries, however, can also be used as the main subjective sleep measurement approach. Five studies provide evidence about the use of sleep diaries alone to measure sleep in adolescents. (Table 5.)

Gaina and colleagues (Gaina et al., 2004b; Gaina, Sekine, Hamanishi, Chen, & Kagamimori, 2005) compared one week of subjective diary data to actigraph data in over 130 healthy Japanese subjects age 13 to 14 years. Subjective reports of sleep latency, sleep start, sleep end, and assumed sleep were significantly associated with objective actigraph data for both genders, with correlations ranging from 0.49 to 0.99, $p < 0.001$ (Gaina et al., 2004b). Correlations were lower for nighttime awakenings ($r = 0.55$ to 0.68) and sleep latency ($r = 0.66 – 0.77$), where adolescents tended to underestimate how many times they awoke during the night and overestimate how long it took them to fall asleep. The associations were consistently stronger for school-days than for weekend days, and the strength of the associations showed a decreasing pattern over the one-week period (Gaina et al., 2005b).

Bertocci and colleagues (2005) collected sleep diary information for one week from a group of 51 children and adolescents with major depressive disorder (MDD) and 42 matched controls, age 8 to 16 years old. While depressed subjects rated their sleep as more disturbed than the control subjects, follow-up polysomnography showed no objective evidence to support the diary complaints of poor sleep reported by adolescents with MDD. In fact, the subgroup of MDD youth with the worst sleep complaints appeared to sleep better in the polysomnography laboratory. The authors' findings raise questions about how adolescents with behavioral and emotional problems perceive their sleep and sleep problems.

Tsai and Li (2004) collected sleep diary data from 237 Taiwanese college students for one week, assessing sleep time variables as well asking about sleep quality and any significant events. Hansen and colleagues (2005) reported on diary data collected for one month at four

separate times from 55 American high school students taking a biology class. Problems with attrition were noted in the Hansen study, but no validity or reliability estimates for the diary data were given in either of these studies.

In summary, there is a need for studies to evaluate the use of a sleep diary alone as a valid and reliable sleep measurement approach with adolescents. There is some evidence to support the short-term use of diaries for healthy adolescents on regular schedules, but diaries may be problematic when used to collect sleep data on non-school days, from adolescents who keep irregular schedules, and from adolescents with significant emotional issues. The burden of daily diary recording may result in decreased reliability over time, and this approach may have limited feasibility and problems with missing data when used with adolescents who are symptomatic on active cancer treatment.

Implications for Practice and Research

Although much has been learned about the importance of sleep for adolescents' well-being, more research is needed to understand sleep-wake disturbances in adolescents with cancer as they receive acute treatment and when they become long-term survivors. Because a limited number of sleep studies have been conducted with adolescents with cancer, knowledge about their sleep problems often emerges from studies with younger children or older adults. To facilitate adolescent oncology sleep research, investigators need to work toward a sound measurement approach using a standard set of sleep parameters. Sleep researchers need to report information about the feasibility, reliability, and validity of sleep measures when they are used with adolescents, and studies with larger samples of adolescents with cancer are needed.

This review described the use of actigraphy, self-report questionnaires, and diaries used to measure sleep in healthy and chronically ill adolescents. Actigraphy is an objective approach that has been used successfully with chronically ill adolescents, including adolescents with cancer. When combined with diary questions to elicit subjective data, actigraphy offers a valid and reliable measurement approach for adolescent oncology sleep research, especially when at least five nights of usable data are recorded. When using this approach, however, adolescent oncology sleep researchers need to follow recommended standards for the use and analysis of data as well as account for the necessary technological and financial requirements.

Although there are several adolescent-appropriate sleep questionnaires currently used in sleep research, none address the full set of sleep parameters recommended for oncology patients, and none have been tested with adolescents on cancer treatment or adolescent cancer survivors. Researchers need to explore whether some of the existing instruments can be tailored for use with adolescent oncology patients. Other questionnaires that have been validated with adults with cancer, such as the Pittsburgh Sleep Quality Index (PSQI) (Beck, Schwartz, Towlsey, Dudley, & Barsevick, 2004), the General Sleep Disturbance Scale (GSDS) (Miaskowski et al., 2006), or the Clinical Sleep Assessment (Lee & Ward, 2005) may also be acceptable for trials with adolescents. Although the Pittsburgh Sleep Quality Index has been used in several studies with healthy older adolescents and young adults (Brown, Buboltz, & Soper, 2002; Carney, Edinger, Meyer, Lindman, & Istre, 2006; Pilcher, Schoeling, & Prosansky, 2000), no psychometric data was available about its use with these samples. Sleep diaries also need to be evaluated as a potential short-term measurement approach with adolescent oncology patients.

Once accurately described, the sleep-wake disturbances of adolescents with cancer should be compared with those of healthy cohorts of adolescents for clinical interpretation. Information about normal sleep variables is available for healthy adolescents, and these parameters can be

applied to the oncology population to identify and study the most serious sleep-wake disturbances (National Sleep Foundation, 2000).

The impact of sleep-wake disturbances on adolescents' well-being is an especially important consideration for oncology health care providers. Just as with healthy adolescents, insufficient sleep may contribute to a variety of risks and negative consequences for adolescents who are also dealing with the effects of cancer. Insufficient sleep may further compromise adolescents' abilities to continue with their normal activities at school and with their friends as well as to overcome the emotional and mood disturbances that accompany a cancer diagnosis. Sound approaches to the measurement of sleep are critical to advance symptom prevention and management research that will improve the quality of life for adolescents with cancer, both during and after their treatment has ended.

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Table 1

Nine sleep parameters recommended for evaluation of sleep-wake disturbances

Sleep parameter	**Definition**
Total sleep time	Number of minutes of sleep in bed
Sleep latency	Number of minutes between getting into bed and falling asleep
Awakenings	Number of awakenings during the sleep period
Wake after sleep onset (WASO)	Number of minutes awake after initial sleep onset
Daytime napping	Number of minutes of sleep during daytime naps
Daytime sleepiness	Number of episodes of falling asleep without intention
Quality of perceived sleep	Subjective assessment of quality
Circadian rhythm	Bio-behavioral phenomenon that repeats approximately every 24 hours
Sleep efficiency	Number of minutes of sleep divided by the number of minutes in bed

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Table 2

Studies that used actigraphy with adolescent samples

	Author/year/country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Number of nights recorded	Comments
1	Acebo et al., 1999 US	Healthy	36	Range = 11-16y	58% female; 87% Caucasian	7	Loss of 10% of nights due to technical problems and 8% due to irreconcilable differences between diary and actigraph.
2	Armitage et al., 2004 US	Major depressive disorder (MDD) and healthy controls	59 with MDD and 41 healthy controls	Range = 8-17y	51% female	5	95% compliance for 5 nights of data
3	Beebe et al., 2007 US	Overweight and healthy controls	60 overweight and 20 healthy controls	Mean age = 13.1y (overweight) 12.6y (controls)	67% female, 40% Caucasian (overweight); 64% female, 46% Caucasian (controls)	7	84% wore actigraph at least 5 nights, 62% at least three school nights, 78% at least two non-school nights
4	Bursztein et al., 2006 Israel	Headache and healthy controls	28 with headache and 108 healthy controls	Range = 7-14y	Headache: 50% male; Healthy controls: 39% male	5	No problems reported with actigraphs.
5	Carskadon et al., 1998 US	Healthy	32 9th graders and 26 10th graders	Mean age = 15.0 y	62% female	14	Loss of less than 1 night of data per student due to lack of concordance between self-report and actigraph record
6	Cousins et al., 2007 US	History of substance abuse	34	Mean age = 15.9y	50% female; 47% Caucasian	7	An average of 5.08 nights of data per subject.
7	Franck et al., 1999 US	HIV infection and healthy controls	18 with HIV-infection and 15 healthy controls	Mean age = 11.0 y	61% male; 39% Caucasian, 28% African American	3 (first night data discarded)	Reported problems with broken actigraph straps and removal of actigraphs
8	Gaina et al., 2004b Japan	Healthy	42	Mean age = 14.2y; range = 13-14y	100% male	7	7% of data lost due to subject ‘forgot to wear actigraph’ and artifact during recording. 5% of subject removed actigraph due to allergic reaction.
9	Gaina et al., 2005b Japan	Healthy	91	Range = 13-14 y	52% female	7	3% of data was not usable due to “problems with actigraphy recording.”

	Author/year/country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Number of nights recorded	Comments
10	Gedaly-Duff et al., 2006 US	Acute lymphoblastic leukemia (ALL)	9	Mean age = 11.0 y; Range = 8-16y	56% female; 78% Caucasian	3	Reported 100% compliance
11	Hinds et al., 2007b US	Hospitalized for chemotherapy for solid tumor or acute myeloid leukemia (AML)	29	Mean age = 12.5; Range = 7-18y	59% female; 72% Caucasian, 14% African American, 14% Hispanic	2-3	1 patient (3%) withdrew and 1 actigraph (3%) malfunctioned.
12	Johnson et al., 2007 US	Healthy	164	Mean age = 13.7y	53% African American	5-7	No problems reported
13	Oyane & Bjorvatn, 2005 Norway	Autism and Asperger syndrome	15	Mean age = 19.6y	Not reported.	14	5 subjects (33%) refused to wear the Actiwatch.
14	Sadeh et al., 2000 Israel	Healthy	53	Mean age = 11.8y; Range = 9.9-12.7y	51% male	4-5 school nights	No report of problems.
15	Sadeh et al., 2002 Israel	Healthy	51	Mean age = 11.8y	51% male	5 school nights	Actigraphy repeated on 6 subjects (12%) due to technical failure or illness.
16	Sadeh et al., 2003 Israel	Healthy	35	Mean age = 11.6y	51% male	5 school nights	No report of problems.
17	Sangal et al., 2006 USA	Attention-deficit hyperactivity disorder (ADHD)	85	Mean age = 10.1y; Range = 6-14y	75% male; 62%Caucasian	7 (3 intervals)	3% of subjects had unreliable actigraphy data.
18	Teixeira et al., 2007 Brazil	Healthy	92	Range = 14-21 years	52% female	7	22% data lost due to actigraph malfunction
19	Wolfson et al., 2003 US	Healthy	302	Mean age = 16y; grades 9-12	65% female; 75% Caucasian	8	Loss of less than one scorable night per subject.

Table 3

Self-report sleep questionnaires used with adolescents

	Author/Year	Domains (# of items)	Period of recall	Scoring
Adolescent Sleep-Wake Scale	LeBourgeois, Giannotti, Cortesi, Wolfson, & Harsh, 2005	Sleep behaviors and sleep quality in 12-18 year olds (28) • Going to bed (5) • Falling asleep (6) • Maintaining sleep (6) • Reinitiating sleep (6) • Returning to wakefulness (5)	1 month	Scale ranges from 1-6, and higher scores indicate better sleep quality.
Adolescent Sleep Hygiene Scale	LeBourgeois, Giannotti, Cortesi, Wolfson, & Harsh, 2005	Sleep facilitating and sleep-inhibiting practices in 12-18 year olds (28) • Physiological (5) • Cognitive (6) • Emotional (3) • Sleep environment (4) • Daytime sleep (1) • Substances (2) • Bedtime routine (1) • Sleep stability (4) • Bed/bedroom sharing (2)	'past months'	Scale ranges from 1-6, and higher scores indicate better sleep hygiene.
Epworth Sleepiness Scale	Johns, 1991	Sleepiness (8)	'recent time'	4-point Likert scale (0 = would never doze, 3 = high chance of dozing)
Pediatric Daytime Sleepiness Scale	Drake et al., 2003	Sleepiness (8)	Not specified	5 point Likert scale (0 = never, 4 = always)
School Sleep Habits Survey	Carskadon, Seifer, & Acebo, 1991	• Daytime sleepiness scale (10) • Sleep/wake problems behavior scale (15) • Depressive mood scale (6) • Morningness/eveningness (M/E) scale (10)	2 weeks	Higher scores mean greater sleepiness, sleep/wake problems, depression, and
Sleep Habits Questionnaire	Gruber, Sadeh, & Raviv, 1997	Sleep habits, sleepiness, fatigue (20)	Not reported	4 point Likert scale
Sleep Hygiene Awareness and Practices Scale (SHAPS)	Lacks & Rotert, 1986	• Sleep hygiene awareness (13) • Caffeine awareness (18)	1 week	7-point Likert scale

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	Author/Year	**Domains (# of items)**	**Period of recall**	**Scoring**
		• Hygiene practice (19)		
Sleep Quality Index (SQI)	Urponen, et al., 1991	Sleep Quality (8)	1 week	3-point Likert scale
Sleep Questionnaire	Gaina et al., 2005a	Sleep-wake patterns (13) • Bedtimes, wake times, sleep times, desired sleep time, sleepiness, sleep-latency, ease of falling asleep, number of night awakenings, sleep deepness, feelings in the morning, sleep is enough, sleep quality, drowsiness	1 week	Discontinuous variables on a nominal scale

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Table 4

Psychometric properties of self-report sleep questionnaires used with adolescents

Author/Year Country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Reliability and Validity
Adolescent Sleep-Wake Scale					
LeBourgeois et al., 2005 Italy and US	Healthy	1348 (776 Italian and 572 American)	Mean age = 14.6y Range = 12-17 y	49% male; Italian sample: 99% Caucasian; American sample: 78% African American	Reliability Internal consistency: (Chronbach's alpha): • Subscales = .60 -.82. • Full scale = .80 - .86
Adolescent Sleep Hygiene Scale					
LeBourgeois et al., 2005 Italy and US	Healthy	1348 (776 Italian and 572 American)	Mean age = 14.6y Range = 12-17 y	49% male; Italian sample: 99% Caucasian; American sample: 78% African American	Reliability Internal consistency (Chronbach's alpha): • Subscales = .37 - .74 • Full scale = .80
Epworth Sleepiness Scale					
Gibson et al., 2006 Canada	Healthy	3235	Mean age = 16.2y Range = 14-18y	53% male	Reliability Stability: ICC (Intraclass correlation) = 0.88.
Pediatric Daytime Sleepiness Scale					
Drake et al., 2003 US	Healthy	442	Mean age = 11.8 y Range = 11-15y	52% male; 90% Caucasian	Reliability Internal consistency (Chronbach's alpha): • Total scale = .81 • Split-half samples = .80. Validity Construct validity: Factor analysis confirms 1 factor.
Maganti et al., 2006 US	Epilepsy	26 patients and 26 controls	Mean age = 14 y Range = 8 – 18y	65% female	Reliability Internal consistency (Chronbach's alpha): • Full scale = .78
School Sleep Habits Survey					

Author/Year Country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Reliability and Validity
Gau & Soong, 2003 Taiwan	Healthy	1547	9-16 y; Mean age = 12 y	52% male	<u>Reliability</u> <u>Morningness/Eveningness scale</u> • Stability: ICC for sum score = .75 • Internal consistency: Chronbach's alpha = .68 <u>Sleepiness Scale</u> • Stability: Kappa statistic = .27-.51. • Stability: ICC for sum score = .57-.73. • Internal consistency: Chronbach's alpha = .64. <u>Sleep Disturbance Scale</u> • Stability: Kappa statistic = .23-.70. • Stability: ICC for sum score = .48-.86 • Internal consistency: Chronbach's alpha = .45 <u>Validity</u> <u>M/E scale</u> Discriminant validity confirmed between highest and lowest quartiles.
Giannotti et al., 2002 Italy	Healthy	6631	Mean age = 17y Range = 14-18 y	60% female	<u>Reliability</u> Internal consistency (Chronbach's alpha): • Sleepiness Scale = .63 • Sleep/Wake Problems Scale = .71. • Substance Use Scale = .51. • M/E scale = .73.
Wolfson et al., 2003 US	Healthy	302	Mean age = 16 y Range = 14-19 y	65% female; “Mostly Caucasian”	<u>Concurrent validity</u> Pearson correlation with actigraph data: • Survey responses correlated with actigraph data for total sleep time, sleep onset time, and wake time.

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Author/Year Country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Reliability and Validity
					• Correlations were lower for weekend nights (r = .31 - .48) than for weekday nights (r = .53 - .77). By matched-pair t tests with actigraph data: • Schoolnight survey responses for total sleep time and wake time did not differ from actigraph estimates. • Survey schoolnight bedtimes were 8-13 minutes earlier than actigraph (p<.001). • Survey weekend night sleep time was 30 minutes longer than actigraph data (p< .001). • Survey weekend wake times were 55 minutes later than actigraph data (p < .001).
Wolfson & Carskadon, 1998 US	Healthy	3120	13-19 y	52% female; 85% Caucasian	Reliability: Internal consistency (Chronbach's alpha): • Sleepiness scale = .70 • Sleep/wake problems scale = .75.
Sleep Habits Questionnaire					
Sadeh et al., 2000 Israel	Healthy	53	Mean age = 11.8y Range = 9-12 y		Reliability Internal consistency (Chronbach's alpha): • Between .72 and .82 Validity Construct: Factor analysis confirms 2 factors: sleepiness and sporadic daytime sleep.
Sleep Hygiene Awareness and Practices Scale (SHAPS)					
Brown et al., 2002 US	Healthy	124	Mean age = 19.5 y	59% female	Reliability Internal consistency (Chronbach's alpha): • Sleep hygiene awareness = 0.78 • Caffeine knowledge = 0.47

Author/Year Country	Health status of sample	Sample size	Age of sample	Gender and ethnicity of sample	Reliability and Validity
					• Sleep hygiene practices = 0.55 Test-retest: • Sleep hygiene awareness = 0.76, p<.001 • Caffeine knowledge = 0.50, p<0.001 • Sleep hygiene practices = 0.74, p<0.001
Sleep Quality Index					
Bulboltz, et al., 2001 US	Healthy	191	Mean age = 19 y	50% female, 82% Caucasian	Reliability Internal Consistency (Chronbach's alpha) = 0.74
Sleep Questionnaire					
Gaina et al., 2005b Japan	Healthy	91	Mean age = 14.2y Range = 13-14y	52% female	Reliability Test-retest (Kappa statistic): • Bedtime, sleep latency = .46 - .59 • Wakeup, sleep efficiency = .62 - .63 • Sleep perception, sleepiness = .41-.48 Validity Concurrent: Pearson correlation with actigraph (p < 0.01): • r = .65 - .68 for schoolnight bedtime, waketime • r = .50 - .60 for weekend bedtime, waketime • r = .39 for schoolnight sleep period • r = .36-.42 for weekend sleep period

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Table 5

Studies using sleep diary measurement approach

Author/year/country	Health status	Sample size	Age of sample	Gender and ethnicity	Length of diary report
Bertocci et al., 2005 US	Major depressive disorder (MDD) and healthy controls	51 subjects with MDD and 42 healthy controls	MDD group: Mean age = 12.3y Control group: Mean age = 11.9y	MDD group: 55% female, 84% Caucasian Control group: 667% male, 86% Caucasian	1 week
Gaina et al., 2004b Japan	Healthy	42	Range = 13-14 y	100% male	1 week
Gaina et al., 2005b Japan	Healthy	91	Range = 13-14 y	52% male	1 week
Hansen et al., 2005 US	Healthy	60	High school seniors	Not reported	4 1-month intervals
Tsai & Lee, 2004 Taiwan	Healthy	237	Range = 18-24 y	54% male	1 week