



CLINICAL REVIEW

Self-report instruments for assessing sleep dysfunction in an adult traumatic brain injury population: A systematic review

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SUMMARY

Objectives: To review the number and characteristics of self-reported sleep measures used to evaluate impaired sleep/wakefulness in traumatic brain injury (TBI) populations.**Methods:** We conducted a comprehensive peer-reviewed literature search of Medline, Embase, PsycINFO, CINAHL, and various bibliographies. Only standardized self-report measures for evaluating sleep dysfunction and its signs were taken into consideration.**Results:** Sixteen self-report measures used in TBI research and clinical practices were identified. Five were generic, five symptom-related, and six were condition-specific measures. The Pittsburgh sleep quality index and Epworth sleepiness scale were partially validated in post-acute TBI.**Conclusion:** Although no instrument has been specifically developed for TBI patients, there are scientific benefits to using the existing measures. However, additional research is needed to examine their applicability to the TBI population. The design and introduction of a new instrument able to triage sleep-related complaints between depressive, other medical, and primary sleep disorders—with a section for caregiver reports—might assist in the identification of the etiology of sleep dysfunction in persons with TBI. In choosing or developing a sleep measure, researchers and clinicians must consider the specific domains they want to screen, diagnose, or monitor. Polysomnography is recommended for diagnosing specific sleep disorders that cannot be diagnosed solely using a self-report measure.© 2013 Elsevier Ltd. Open access under [CC BY-NC-ND license](http://creativecommons.org/licenses/by-nc-nd/3.0/).

Introduction

Traumatic brain injury (TBI) is a major global health problem. According to the World Health Organization, TBI will surpass many diseases as the major cause of death and disability by the year 2020.¹ With an estimated 10 million people affected annually by TBI, the burden of mortality and morbidity that this condition imposes on society makes it a pressing public health concern.

Recently, there has been growing interest in sleep/wake disturbances, with numerous studies published reporting on sleep problems in patients who sustained a TBI.^{2–8} According to a recent systematic review,⁹ research has shown that patients present a number of different sleep and wakefulness symptoms, including an acute or chronic inability to sleep adequately at night (insomnia¹⁰), chronic fatigue,^{11,12} sleepiness,³ circadian rhythm disturbances,¹⁰ and behavioral manifestations associated with sleep itself. The recognition of the importance of systematically

assessing sleep difficulties in a TBI population has influenced clinical practice and research in the field of TBI. This reflects clinicians' concerns of how there should be better evaluations and treatments for people with TBI who report significant disturbances in sleep/wake cycles post-injury.

Researchers and clinicians have analyzed sleep using both subjective and objective tools. The former are generally questionnaires completed by subjects; the latter are techniques such as polysomnography (PSG),¹³ actigraphy,¹⁴ the multiple sleep latency test (MSLT)¹⁵ and the maintenance of wakefulness test (MWT).¹⁶ PSG evaluates the nocturnal sleep structure by quantifying sleep disturbances. The MSLT quantifies daytime sleepiness. Finally, the MWT evaluates a person's ability to remain alert (i.e., it is a wakefulness test). Unfortunately, these tests are costly and currently require a specialized hospital or sleep clinic setting. In addition, they may not adequately capture the fluctuating nature of some sleep disorders such as insomnia and circadian rhythm sleep disorders. Furthermore, PSG results might be influenced by the first night effect, or the alteration of the sleep structure as a result of being in an unfamiliar environment. Actigraphy is another objective method that has been

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Abbreviations

BSIQ	Brock sleep and insomnia questionnaire	mTBI	mild traumatic brain injury
CBT	cognitive behavioral therapy	MEQ	morningness-eveningness questionnaire
DSM-IV	diagnostic and statistical manual of mental disorders, 4 th edition	MAF	multidimensional assessment of fatigue
DII	diagnostic interview for insomnia	MFI-20	multidimensional fatigue inventory
DBAS	dysfunctional beliefs and attitudes about sleep scale	MSLT	multiple sleep latency test
EDS	excessive daytime sleepiness	PLM	periodic leg movements
ESS	Epworth sleepiness scale	PLMD	periodic limb movement disorder
FSS	fatigue severity scale	PSQI	Pittsburg sleep quality index
GCS	Glasgow coma scale	PSG	polysomnography
ISI	insomnia severity index	PTA	post-traumatic amnesia
ICSD	international classification of sleep disorders	RBD	REM behavior disorder
LSEQ	Leeds sleep evaluation questionnaire	SDQ	sleep disorders questionnaire
LOC	loss of consciousness	SWD	sleep-wake disturbance
MWT	maintenance of wakefulness test	SSS	Stanford sleepiness scale
MOS sleep scale	medical outcomes study sleep scale	SNS	Swiss narcolepsy scale
		TBI	traumatic brain injury
		UNS	Ullanlinna narcolepsy scale

used to study sleep/wake patterns in clinical research and practice. It can conveniently record people's activity/inactivity periods up to 24 h a day over long periods (i.e., weeks or months). Although actigraphs provide useful collateral measures of sleep patterns, especially when the patient's own report is in question,¹⁴ they have been found to be less reliable in distinguishing between quiet wakefulness and sleep.¹⁷ Discrepancies between these subjective and objective measures¹⁸ raise the question as to which type of data is more important: subjective reports of quality of sleep and daytime sleepiness/alertness or objective evaluation reports. Many researchers are now using patient-report scales in assessing sleep, as they believe that self-perceived health outcomes are more significant and of greater relevance to the patients' treatment than objective data. Although it may not be accurate, especially in the TBI population where sleep state misperception is common, questionnaires are often the instruments first used to assess sleep. This is partly because of their cost effectiveness, their ability to capture unique patient experiences, and the added privacy during completion, which can enhance the validity of the responses. Thus, it is necessary and timely to provide a systematic consideration, solid description, and in-depth understanding of the strengths and limitations of the whole range of self-reported measurements utilized in the assessment of sleep dysfunction in TBI research and clinical practice.

Objectives

The purpose of this review was:

1. To identify and comprehensively assess a variety of the existing self-report sleep measures that have been used to evaluate impaired sleep and wakefulness in adults with TBIs in the acute and chronic stages.
2. To examine these instruments' psychometric properties when tested in the TBI population.
3. To outline the strengths and weaknesses of self-report sleep measures when applied to the TBI population.

Methods

Types of studies

All studies focusing on the TBI adult population and that used a standardized patient-report sleep measure were considered for this review.

Search methods for identification of studies

A comprehensive search strategy was performed to identify all relevant studies, using electronic databases as well as manual selection from relevant bibliographies. The following electronic databases were screened for updated results as of July 2, 2011: Medline and PsycINFO (1980 to present), CINAHL (1982 to present) and Embase (1988–2011, week 31). Furthermore, the reference lists of relevant review articles were scanned for published studies that may have been missed by the electronic literature search.

The inclusion criteria were:

- Published, peer-reviewed studies in English that included data on adult subjects with TBI.

The exclusion criteria were:

- Studies that focused on a different topic (e.g., quality of life, fatigue).
- Studies that used measures specifically created for one study only or studies that used adapted measures.
- Letters to editors, reviews without data, case reports, technical reports, or unpublished manuscripts.

Search terms

Under the supervision of an expert librarian, the following key search terms were used: "exp sleep*" or "sleep disorders" along with "exp brain injuries," "craniocerebral trauma," "coma, post-head injury," "head injuries, penetrating," "intracranial hemorrhage, traumatic," or "exp skull fractures"; to this, we added "questionnaires," "self report," "survey," "exp data collection," "tool," "scale," "test," or "exp weights and measures"; finally, we added, to some combination of the above, "exp reproducibility of results," "reliability," or "validity." Appropriate truncations were included. The above search strategy was used only for Embase. For Medline, PsycINFO, and CINAHL, this strategy was slightly altered (Table S1).

Selection of studies and data abstraction

The abstracts and full articles (when abstracts were not available) were thoroughly screened by two independent reviewers in order to ascertain that a self-reported sleep measure had been used in each study. Furthermore, the full texts of all selected articles

were reviewed by the same two independent reviewers for the study purpose when a relevant self-report measure was identified. Measures that met our criteria (i.e., standardized, not modified, main focus on sleep) were extracted for further analysis. Differences of opinion were resolved by discussion. A third reviewer was consulted where consensus could not be reached.

For the assessment of inter-rater reliability, the two reviewers individually performed independent in-depth reviews and completed the review forms. The review forms focused on study design, study population, issues related to the instruments used, item omission rates, measurement issues, analysis, and quality appraisal. Results were presented at a meeting and the merit of each study was discussed. Decisions were made following a full discussion and in the presence of the third reviewer. In one case, the decision to include partial results from the study by Masel et al.¹⁹ (e.g., validation of the Epworth sleepiness scale (ESS) and the Pittsburgh sleep quality index (PSQI) against MSLT) was based on the study's use of a scientifically acceptable method for assessing the psychometric properties of the instrument, despite that not being their main purpose. In this case, the third reviewer was consulted.

Quality assessment

The criteria for evidence-based assessment proposed by Holmbeck et al.²⁰ were used to provide an “evidence-based assessment classification” for each of the measures reviewed (Table 1). The following evidence-based categories were proposed: 1) well-established assessment, 2) approaching well-established assessment, and 3) promising assessment.

Categorization of self-report measures

Instruments for measuring health-related outcomes were grouped into the following categories: 1) condition-specific questionnaires, developed or validated for persons with a specific health condition; 2) generic instruments, designed to differentiate between health conditions; and 3) symptom-related instruments that screen for signs and symptoms.⁴

Descriptive aspects of sleep measures

The descriptive aspects were meant to illustrate the design, content, and possible application of the measures. The following features of self-report sleep measures were reported: general characteristics, purpose/content, method of administration, administration and respondent burden, language (availability of translations), psychometric properties, strengths, and cautions for application in a TBI population (Table S2).

Results

Literature search

The abstracts of studies ($N = 366$) published before July 2, 2011 were retrieved from Medline ($n = 176$), Embase ($n = 38$), PsycINFO ($n = 14$), and CINAHL ($n = 139$). We completed a full text review for 54 articles; following this, we excluded 26 articles, four of which were not peer-reviewed and 22 of which did not meet the inclusion criteria (Fig. 1).

From these 28 studies included in the final analysis, 16 self-report measures were identified (Table 2). Each measure was extracted from the original article, downloaded from the Internet, or an attempt was made to obtain the instrument from its author(s). After a review of the measures, organization by type of measure was completed (Table 3). Of the 16 sleep measures

identified, five were generic in nature (one generic, one quality of sleep, one chronotype, one diagnostic, and one functioning), five were symptom-related (two sleepiness, three fatigue) and six were condition-specific measures (four for insomnia and two for narcolepsy). An additional literature search was carried out to search for key terms in the PubMed database on the psychometric properties of the measures that we extracted.

Study descriptions

Of the final 28 studies, two featured participants from acute care hospitals, nine from inpatient/outpatient rehabilitation settings, and the rest from community settings (Table 1). The most commonly utilized scales were the Pittsburgh sleep quality index (PSQI) and the Epworth sleepiness scale (ESS; 12 studies); the less frequently used ones were the fatigue severity scale (FSS; 5 studies), the morningness–eveningness questionnaire (MEQ), and the insomnia severity index (ISI; 4 studies). The sleep disorders questionnaire (SDQ), the Swiss narcolepsy scale (SNS), the Ullanlinna narcolepsy scale (UNS), the multidimensional fatigue inventory (MFI-20), and the multidimensional assessment of fatigue (MAF) were used in two studies each. The Leeds sleep evaluation questionnaire (LSEQ), the medical outcome scale for sleep (MOS sleep scale), the Brock sleep and insomnia questionnaire (BSIQ), the dysfunctional beliefs and attitudes about sleep scale (DBAS), the diagnostic interview for insomnia (DII), and the Stanford sleepiness scale (SSS) were utilized in one study each (Table 1). The sample size varied from 9²¹ TBI patients to 687.²² In half of the studies, the sample size did not exceed 50. Some studies had subjects with only mild TBI,^{10,21–24} one focused on subjects with severe TBI,¹² and the remainder featured subjects with varying severities of injury. The mean time from the occurrence of the injury ranged from 2.6 months¹¹ to 94.3 months.²⁵ Moreover, variability was found in the age and gender of the participants across studies. The mean age of the study subjects ranged from 21.4²¹ to 51.37²⁵ with the average age among all samples being 35 y of age. The number of men exceeded that of women in all studies, with the percentage of men ranging from 54%²⁶ to 93%.²⁴

Twenty-four^{5,6,8–12,19–23,25,27–39} of the 28 studies aimed to describe sleep dysfunction in the TBI population or discriminate people with sleep disturbances from those with normal sleep patterns. The remaining four studies evaluated effectiveness of treatment interventions.^{24,26,40,41} Two of the 28 studies focused on the psychometric evaluation of self-report measures in a TBI population^{19,30} (Table 2). Fichtenberg et al.³⁰ reported on the validity of the PSQI in a sub-acute TBI sample of 50 patients in distinguishing participants with insomnia according to DSM-IV criteria.³⁰ The overall rate of agreement of the PSQI with DSM-IV diagnosis was found to be 94%, with a sensitivity of 100% and specificity of 96%. When the PSQI-derived calculations of sleep-onset latency, sleep duration, and sleep-efficiency were compared with a sleep diary, mean paired differences were small and Pearson correlation coefficients ranged from 0.633 to 0.796 ($p < 0.05$). The proposed global PSQI cut-off score of 8 was found to be able to distinguish 96% of insomnia cases correctly, and a cut-off score of 9 distinguished 98%. The concurrent validity of the PSQI and the ESS was also reported in a study by Masel et al.¹⁹; this study investigated ESS and PSQI scores and their relationships to the mean scores on the MSLT in 71 TBI patients 3–27 y post-injury. Masel et al. found a nonsignificant correlation between the self-report scores and the mean MSLT sleep latency.

Measure descriptions

The majority of the measures reviewed, with the exception of the SDQ, DBAS, DII, SNS, and UNS, are available online and hence

Table 1
Quality assessment in accordance with the evidence-based assessment proposed by Holmbeck et al.²⁰

#	Questionnaires	Frequency of use by different investigators	Frequency of use by same investigators ^b	Details for critical evaluation/replication	Reliability ^a	Validity ^a
<i>Generic measures</i>						
1.	Leeds sleep evaluation questionnaire (LSEQ)	1×; Lee et al. ⁴¹		+ No cost; can be obtained online at: http://www.epgonline.org/documents/insomnia/leeds-sleep-evaluation-questinaire.pdf	–	–
2.	Medical outcome for sleep (MOS sleep scale)	1×; Rao et al. ³⁶		+ No cost; can be obtained online at: http://www.rand.org/content/dam/rand/www/external/health/surveys_tools/mos/mos_sleep_survey.pdf	–	–
3.	Morningness-eveningness questionnaire (MEQ)	2×; Ayalon et al. ¹⁰	3× by one team; Parcell et al. ⁷ ; Shekleton et al. ³⁷ ; Steele et al. ³⁸	+ Can be obtained and completed online at: http://www.cet-surveys.org/Dialogix/servlet/Dialogix?schedule=3&DIRECTIVE=START	–	–
4.	Sleep disorders questionnaire (SDQ)	2×; Guilleminault et al. ³² ; Williams et al. ²¹	–	– Not available to public: Contact – Alan B. Douglass, M.D., Psychiatry Department, Room 2951 CFOB, University of Michigan, Ann Arbor, MI 48109–0704, U.S.A.	–	–
5.	Pittsburgh sleep quality index (PSQI)	9×; Bloomfield et al. ³⁹ ; Gosselin et al. ²³ ; Kraus et al. ²² ; Mahmood et al. ⁵ ; Masel et al. ¹⁹ ; Williams et al. ²¹	3× by one team; Fichtenberg et al. ²⁹ ; Fichtenberg et al. ³⁰ ; Fichtenberg et al. ³¹ 2× by one team; Parcell et al. ⁷ ; Shekleton et al. ³⁷ 2× by one team; Bushnik et al. ¹¹ ; Englander et al. ²⁸	+ Can be obtained online at: http://www.sleep.pitt.edu/includes/showFile.asp?ftype=doc&fID=2532	–	Sensitivity – 83–93%; specificity – 100% (dx of insomnia) for sleep diary sleep variables: $r = 0.64–0.80$ (Fichtenberg et al. ³⁰); for MSLT: $\rho = 0.07$ (Masel et al. ¹⁹)
<i>Condition-specific measures</i>						
6.	Brock sleep and insomnia questionnaire (BSIQ)	Williams et al. ²¹		– Not available to public: To obtain BSIQ, must contact author Dr. Kimberly Cote: kcote@brocku.ca	–	–
7.	Dysfunctional beliefs and attitudes about sleep scale (DBAS)	Ouellet et al. ²⁶		– Not available to public: For information regarding obtaining the DBAS, etc contact author C.M. Morin: cmorin@psy.ulaval.ca	–	–
8.	Insomnia severity index (ISI)	2×; Bloomfield et al. ³⁹	3× by one team; Ouellet et al. ⁶ ; Ouellet et al. ³⁴ ; Ouellet et al. ²⁶	+ No cost; can be obtained online at: http://www.mytherapysession.com/PDFs/InsomniaSeverityIndex.pdf	–	–
9.	Diagnostic interview for insomnia (DII)	Ouellet et al. ²⁶		– Not available to public: For information regarding obtaining interview questions, etc. contact author C.M. Morin: cmorin@psy.ulaval.ca	–	–
10.	Swiss narcolepsy scale (SNS)	–	2× by one team; Baumann et al. ²⁷ ; Kempf et al. ³³	– Not available to public: Those interested in using the measure should contact: Prof. Claudio L. Bassetti, Neurologische Universitätspoliklinik, Universitätsspital Zurich, Fraeunklinikstrasse 26, Zurich 8091, Switzerland. Fax: +41 255 4649; email: Claudio.bassetti@usz.ch	–	–
11.	Ullanlinna narcolepsy scale (UNS)	–	2× by one team; Baumann et al. ²⁷ ; Kempf et al. ³³	– Not available to public: Those interested in using the instrument must contact: Christer Hublin MD, Department of Neurology, University of Helsinki, Haartmanink. 4, SF-00290 Helsinki, Finland. Fax +358/04714009	–	–
<i>Symptom-related measures</i>						
12.	Epworth sleepiness scale (ESS)	9×; Chaumet et al. ¹² ; Fichtenberg et al. ³⁰ ; Gosselin et al. ²³ ; Guilleminault et al. ³² ; Lee et al. ⁴¹ ; Ruff et al. ²⁴	3x by one team; Parcell et al. ³⁵ ; Parcell et al. ⁷ ; Shekleton et al. ³⁷ 2× by one team; Kaiser et al. ⁴⁰ ; Kempf et al. ³³ 2× by one team; Masel et al. ¹⁹ ; Wilde et al. ²⁵	+ No cost; can be obtained online at: http://barrythompsonmd.com/wp-content/uploads/2009/10/Epworth-Sleepiness-Scale.pdf	–	for MSLT: $\rho = -0.16$ (Masel et al. ¹⁹)
13.	Stanford sleepiness scale (SSS)	1× Guilleminault et al. ³²		+ Can be obtained online at: http://www.stanford.edu/~dement/sss.html	–	–
14.	Fatigue severity scale (FSS)	3×; Chaumet et al. ¹²	2× by one team; Kaiser et al. ⁴⁰ ; Kempf et al. ³³ 2× by one team; Bushnik et al. ¹¹ ; Englander et al. ²⁸	+ No cost; can be obtained online at: http://www.multiple-sclerosis.org/fatigueeverityscale.html	–	–

15. Multidimensional fatigue inventory (MFI-20)	–	2× by one team; Ouellet et al., 2006; Ouellet et al., 2007	–	–, Not available to public: Investigators interested in using the instrument should contact first author (E.M.A. Smets); for academic use, permission granted at no charge
16. Multidimensional assessment of fatigue (MAF)	–	2× by one team; Bushnik et al., 2007; Englander et al., 2010	–	+ The MAF can be obtained online at: http://www.son.washington.edu/research/maf/users-guide.asp .

^a In relation to TBI population.
^b For the purpose of the assessment if at least two researchers of the group are present in studies featuring the same measure, they were included in the “frequency of use by same investigators” category. MSLT: multiple sleep latency test.

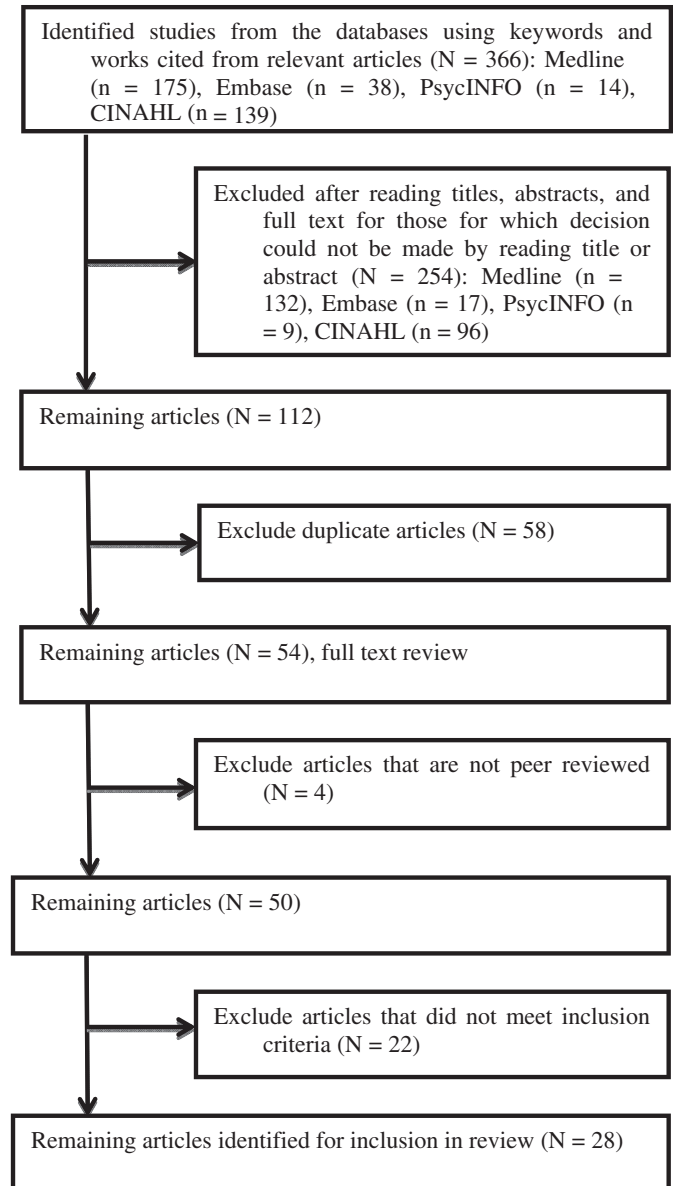


Fig. 1. Flow diagram for selection of studies.

accessible by the public. The reporting period for sleep evaluation varies across the measures. The LSEQ, MEQ, DBAS, SNS, UNS, and DII do not have a recall period specified; the MFI uses the timeline “lately,” the SSS uses “present,” and the ESS refers to “recent times”; furthermore, the FSS refers to the past week; the ISS, to the past two weeks; the MOS and SDQ, to the previous four weeks; and the PSQI, to the previous month. The number of items ranges from a single item (SSS) to 175 items (SDQ), most having between 7 and 20 items. The format of response options varies greatly across all measures. The majority of the instruments were developed in English and some subsequently translated into other languages (Tables S3–S5).

Fatigue measures

When reviewing the self-report measures for the assessment of sleep dysfunction post-TBI, we noted that excessive daytime sleepiness is a symptom that requires major scientific and clinical attention due to its association with several serious medical conditions. The consensus among sleep researchers and clinicians was

Table 2

Peer-reviewed publications addressing sleep dysfunction and its marks in TBI population; the self-report sleep measures used in these studies are listed.

Authors	TBI sample size	TBI study setting	Injury severity (% of total), time since injury (TSI)	Mean age or age \pm SD	Gender (M/F, %)	Study purpose	Self-report sleep measure
Ayalon et al. ¹⁰	42 (mild)	Long-term community residence	GCS: 13–15: 100 TSI: NI	26	80/20	To describe the physiologic and behavioral characteristics of circadian rhythm sleep disorders following mTBI in patients complaining of insomnia	MEQ
Baumann et al. ²⁷	65	Acute care (hospital)	GCS: 13–15: 40 9–12: 23 3–8: 37 TSI: 3.3 mo (mean)	39 \pm 17	86/14	To delineate the frequency and clinical characteristics of sleep/wake disturbances (SWD) and to assess CSF hypocretin 1 levels 6 mo after TBI	UNS, SNS
Bloomfield et al. ³⁹	44	Long-term community residence	Based on GCS, LOC, PTA mTBI: 11 modTBI: 21 sTBI: 68 TSI: 71.5 mo	46	86/14	To examine whether poor sleepers post-TBI had poorer sustained and general attention functioning than good sleepers post-TBI	PSQI, ISI,
Bushnik et al. ¹¹	51 (moderate/severe)	Inpatient rehab (medical center)	GSC: NI TSI: 3 time points: 2.6 mo, 12.6 mo, and 23.2 mo	31	76/24	To qualify self-reported fatigue and associated factors during the first 2 y after TBI	PSQI, MAF, FSS
Chaumet et al. ¹²	36 (severe)	Vocational-adjustment program (rehab department)	Class by Marshall: Diffuse injury I: 11.1 Diffuse injury II: 52.7 Diffuse injury III: 13.8 Diffuse injury IV: 5.5 TSI: > 6 mo	33.2 \pm 10.9	78/22	To investigate how fatigue could affect driving performance in TBI patients	FSS, ESS
Englander et al. ²⁸	119 (self-report)	Long-term community residence (rehab center)	GCS: NI TSI: 9 \pm 7.6 y	40 \pm 12	66/34	To define association between fatigue after TBI and abnormalities in sleep, mood, cognition, physical functioning and neuroendocrine axes	MAF, FSS, PSQI
Fichtenberg et al. ²⁹	91	Outpatient rehab program (hospital)	GCS: 13–15: 33 9–12: 21 3–8: 46% TSI: 3.3 mo (mean)	33.8 \pm 14.5	59/41	To investigate the relationship between insomnia and select demographic, injury and psychological variables in post-acute TBI	PSQI
Fichtenberg et al. ³⁰	91	Outpatient rehab program (hospital)	GCS: 13–15: 33 9–12: 21 3–8: 46 TSI: 3.3 mo (mean)	33.8 \pm 14.5	59/41	To examine the utility and validity of the PSQI for insomnia screening in post-acute TBI	PSQI, ESS
Fichtenberg et al. ³¹	50	Outpatient rehab program	GCS: 13–15: 42 9–12: 18 3–8: 40 TSI: 3.8 mo (mean)	36.5	56/44	To establish the frequency of insomnia in a post-acute TBI population and to compare it with insomnia rates among other rehabilitation outpatients	PSQI
Gosselin et al. ²³	10 (mild)	Long-term community residence	GCS: 13–15: 100 TSI: NI	24.3 \pm 6.1	70/30	To investigate the effect of sport-related concussions (mild TBI) on subjective and objective sleep quality	PSQI, ESS
Guilleminault et al. ³²	184 (head trauma pts)	Long-term community residence	Coma >90 min: 38 LOC < 90 min: 49 Neck trauma: 9 Grogginess: 3 TSI: 15.5 \pm 5 y	M: 39 \pm 12.5; F: 34 \pm 8	74/26	To assess objectively hypersomnia after head trauma and to assess relationship between head trauma and daytime sleepiness	SDQ, SSS, ESS
Kaiser et al. ⁴⁰	20	Surgical intensive care unit	GCS: Plac: 8 \pm 4 Treat: 7 \pm 4 TSI: Plac: 2 \pm 1.2 y Treat: 1.8 \pm 0.9 y	Placebo: 43 \pm 19 Treat: 37 \pm 9	Placebo: 90/10 Treat: 80/20	To assess the effect of daily modafinil on post-traumatic EDS and fatigue. Prospective, double-blinded, randomized placebo controlled pilot study	FSS, ESS
Kempf et al. ³³	51	Long-term community residence	GCS: 13–15: 42 9–12: 22 3–8: 38 TSI: 6 mo	40 \pm 16	84/16	To assess the prevalence and characteristics of post-traumatic SWD 3 y after trauma	ESS, FSS, UNS, SNS

Kraus et al. ²²	687 (mild)	Long-term community residence	GCS: 13–15: 100 TSI: 3 mo	Age range: 18–34: 59.8%; 35–54: 32.8%; 55–64: 7.4% 38.8	64/36	To compare the sequelae of TBI 3 mo post-injury between mild TBI with the non-head injury patients	PSQI
Lee et al. ⁴¹	30 (mild to moderate)	Post-acute (hospital)	Assessment by McAllister: NI TSI: 32.2 days (mean)		80/20	To investigate the effect of methylphenidate (MPD) and sertraline (SER) compared with placebo on various neuropsychiatric sequelae associated with TBI	LSEQ, ESS
Mahmood et al. ⁵	87	Outpatient neuro-rehab program	GCS: 13–15: 28 9–12: 22 3–8: 50 TSI: 2.3 mo	33.7	56/44	To examine the relation between sleep disturbance and neurocognitive ability among TBI patients	PSQI
Masel et al. ¹⁹	71	Residential rehab institute	GCS (reported in 56%): Non-hypersomnia: 6 ± 4 Post-traumatic hypersomnia: 7 ± 5 Hypersomnia with abnormal indices: 8 ± 5 TSI: 38 ± 60 mo	32 ± 11	62/38	To determine the prevalence, demographic and causes of EDS in TBI adults and to investigate the relations between self-report and objective measures of hypersomnolence	ESS, PSQI
Ouellet et al. ⁶	14	Long-term community residence	GCS: mild: 29 Mild–mod: 7 Mod: 29 Mod–severe: 21 Severe: 14 TSI: 20.96 mo	30.36 ± 9.67	64/36	To compare subjective and objective measures (PSC) of sleep in TBI suffering from insomnia and in control	ISI
Ouellet et al. ³⁴	452	Long-term community residence	GCS: 13–15: 59.9 9–12: 23.3 3–8: 37 TSI: 7.8 y	40.2 ± 13.1	65/35	To document the frequency of insomnia (DSM-IV and ICSD criteria); to identify potential predictors of insomnia in persons with TBI	ISI, MFI significant other version of the ISI
Ouellet et al. ²⁶	11	Outpatient rehab center	CGS: 3–14, evaluation by multidisciplinary team, standard criteria used	27.3 (mean)	54/46	To test the efficacy of CBT (stimulus control, sleep restriction, cognitive restructuring, sleep hygiene education and fatigue management) for insomnia associated with TBI	ISI, MFI, DBAS, DII
Parcell et al. ³⁵	63	Community-based outpatient rehab center	GCS: 9.6 ± 0.57 GCS: 12–15: 8 9–12: 13 3–8: 27 varTBI: 14 TSI: 230 days (mean)	32.5 ± 1.7	57/43	To explore subjective sleep reports from chronic TBI and to examine the extent and nature of sleep complaints	ESS
Parcell et al. ⁷	10	Inpatient rehab (hospital)	GCS: 10.8 ± 1.0 GCS: various: 20 9–12: 40 3–8: 40 TSI: 516 ± 124 days	38.8 ± 4.3	60/40	To evaluate changes in sleep quality and objectively assessed sleep parameters after TBI and investigate the relationship between these changes and mood and injury characteristics	PSQI, ESS, MEQ
Rao et al. ³⁶	54	Post-acute (community)	GCS: 13–15: 65 9–12: 11 3–8: 19 TSI: >3 mo	43.2 ± 17.7	59/41	To assess the prevalence of and risk factors for sleep disturbances in the acute post-traumatic brain injury period	MOS-sleep scale
Ruff et al. ²⁴	74 (mild)	Regional polytrauma center	The criteria for mTBI: LOC <30 min duration of any alteration in mental state <24 h, and period of PTA <24 h. TSI: NI	29.4 ± 2.9	93/7	To examine whether 9 weeks of prazosin (alpha-adrenergic blocking agent, able to block nightmares) together with sleep hygiene counseling would improve sleep, headaches and cognitive performance	ESS
Shekleton et al. ³⁷	23	Inpatient rehab (hospital)	GCS: 8.8 ± 3.7 ^{3–14} TSI: 429.7 ± 287.6 days	32.5 ± 12.0	74/26	To investigate sleep/wake disturbances and their underlying mechanisms in TBI patients sample	PSQI, ESS, MEQ
Steele et al. ³⁸	10	Outpatient rehab (hospital)	GCS: 10.9 ± 1.01 ^{6–14} TSI: 516 ± 124.04 days	37.8 ± 4.38	60/40	To investigate sleep timing following TBI using DLMO and MEQ	MEQ
Williams et al. ²¹	9 (mild)	Long-term community residence	GCS: 13–15: 100 TSI: 27.8 ± 15.5 mo	21.4 ± 2.4	67/33	To characterize the extend and nature of disturbed sleep after mTBI and to determine whether sleep disturbances were more psychophysiological, psychiatric or idiopathic insomnia	PSQI, SDQ, BSIQ

(continued on next page)

Table 2 (continued)

Authors	TBI sample size	TBI study setting	Injury severity (% of total), time since injury (TSI)	Mean age or age \pm SD	Gender (M/F, %)	Study purpose	Self-report sleep measure
Wilde et al. ²⁵	35 (Non-OSA: 16, OSA: 19)	Post-acute (medical centers)	GCS: Unknown : non-OSA: 50; OSA: 53 Moderate : non-OSA:12; OSA:16 Moderate/severe: non-OSA :19; OSA:5 Severe: non-OSA: 19; OSA: 26 TSI (avg.): 94.3 \pm 152.1 mo	Non-OSA: 47.25 \pm 9.26 OSA: 51.37 \pm 14.95	Non-OSA: 75/25 OSA: 90/10	To examine the impact of comorbid OSA on the cognitive functioning in TBI patients	ESS

Abbreviations: BSIQ, Brock sleep and insomnia questionnaire; CBT, cognitive behavioral therapy; DBAS, dysfunctional beliefs and attitudes about sleep scale; DSM-IV, diagnostic and statistical manual of mental disorders, 4th edition; ESS, Epworth sleepiness scale GCS, Glasgow coma scale; LCSD, international classification of sleep disorders; ISI, insomnia severity index; LOC, loss of consciousness; LSEQ, Leeds sleep evaluation questionnaire; MEQ, morningness-eveningness questionnaire; MFI-20, multidimensional fatigue inventory; modTBI, moderate TBI; MOS sleep scale, multiple outcomes study sleep scale; NI, not included; OSA, obstructive sleep apnea; PSQI, Pittsburgh sleep quality index; PTA, post-traumatic amnesia; SDQ, sleep disorders questionnaire; TSI, time since injury; VarTBI, varying severities of TBI.

Table 3
Grouping of sleep measures according to type.

Type of Instrument	Name of instrument
Generic – quality of sleep	Leeds sleep evaluation questionnaire (LSEQ) ⁴¹
Generic – functioning	Medical outcome scale for sleep (MOS) ³⁶
Generic – chronotype	Morningness-eveningness questionnaire (MEQ) ^{8,10,37,38}
Generic – diagnostic	Pittsburgh sleep quality index (PSQI) ^{5,11,19,21–23,28,29,31,37,39}
Generic	Sleep disorders questionnaire (SDQ) ^{21,32}
Condition-specific insomnia	Brock sleep and insomnia questionnaire (BSIQ) ²¹
Condition-specific insomnia – cognition	Dysfunctional beliefs and attitudes about sleep scale (DBAS) ²⁶
Condition-specific insomnia	Insomnia severity index (ISI) ^{6,26,34,39}
Condition-specific insomnia	Diagnostic interview for insomnia (DII) ²⁶
Condition-specific narcolepsy	Ullanlinna narcolepsy scale (UNS) ^{27,33}
Condition-specific narcolepsy	Swiss narcolepsy scale (SNS) ^{27,33}
Symptom – sleepiness	Stanford sleepiness scale (SSS) ³²
Symptom – sleepiness	Epworth sleepiness scale (ESS) ^{8,12,19,23–25,30,32,33,35,37,40,41}
Symptom – fatigue	Fatigue severity scale (FSS) ^{11,12,28,33,40}
Symptom – fatigue	Multidimensional fatigue inventory (MFI-20) ^{6,34}
Symptom – fatigue	Multidimensional assessment of fatigue (MAF) ^{11,28}

that sleepiness is a basic physiological state and its presence and severity can be determined by the readiness with which sleep onset occurs.⁴² As with other self-reported symptoms, one's perception influences the severity and presentation of the complaint. There was great variability in the perception of excessive sleepiness—some viewed sleepiness as a period of lapses in attention, others as reduced cognitive ability, the inability to comprehend information and act quickly, or a reduction in activity. However, the last of those concepts was more relevant to impaired alertness.⁴³ According to the studies, it appears to be easier to perceive a lack of energy than any degree of sleepiness. This often results in confusion as to the symptoms of fatigue, excessive sleepiness, and impaired alertness.⁴⁴ The perception of sleepiness was also influenced by the length of the period of sleep deprivation. Chronically sleep-deprived persons, having adjusted to their impairment, are less likely to recognize their degree of sleepiness, despite reporting a lack of energy. Distinguishing excessive sleepiness, fatigue, and impaired alertness can be difficult, especially in the TBI population; however clinical history, and, in research, the inclusion of additional items/scales to differentiate between the three symptoms may be helpful in identifying the underlying pathology.

Quality assessment

The quality of the measures was evaluated using the evidence-based assessment proposed by Holmbeck et al.²⁰ None of the measures met the criteria for “well-established,” “approaching well-established,” or “promising” ratings in a TBI population (Table 1). While Fichtenberg et al. assessed the concurrent validity of the PSQI, the reliability of the measure was not reported.³⁰ Similarly, Masel et al.¹⁹ reported the concurrent validity of the ESS and the PSQI against MSLT scores, but not the reliability. Good validity does not imply good reliability, and the instrument therefore cannot be considered as valid in a TBI population without sufficient reliability data.

Discussion

This systematic review covers the various sleep-related self-report measures used in TBI research and clinical practice to date. An extensive search strategy led to the identification of 16

measures from more than 100 currently available in the field of sleep medicine.⁴⁵ These measures were reviewed and comprehensively described (Supplementary Tables S2, S3, S4), providing potential users with information on what has been utilized and measured regarding sleep in the TBI population, which can aid in instrument selection.

Twelve out of the 16 measures presented good psychometric data in the population of people with TBI as well as in other study populations, providing an empirical base for further testing of their psychometric properties in a TBI population. However, when the PSQI and the ESS were tested for concurrent validity along with other measures in the TBI population, findings were inconsistent. Fichtenberg et al.³⁰ reported good concurrent validity of the PSQI when tested against a sleep diary and clinical diagnoses of insomnia. When Masel et al.¹⁹ evaluated the PSQI and the ESS against the MSLT, they found no significant correlations. While this is expected for the relationship between the PSQI and the MSLT, due to the different dimensions of the constructs being assessed, the results were unexpected for the relationship between the ESS and the MSLT, raising concern about the clinical utility of self-report measures in people with TBI. Some researchers stressed that severe TBI participants under-reported changes in their sleep due to impaired self-awareness or because they did not perceive the sleep disturbance to be problematic relative to other disabilities.^{3,37} Others^{2,5} reported that milder TBIs were associated with increased self-reported sleep disturbance, questioning the ability of such measures to properly assess sleep post-TBI. Any further discussion regarding the utilization of self-report sleep measures must consider how severity/localization of injury relates to the changes in awareness that may influence the responses of people with TBI.⁴⁶ A person with moderate to severe TBI, or a person with TBI with pre-existing sleep difficulties might be unable to fully grasp the changes to their sleep since the injury, or report on sleep quality and quantity with sufficient insight. Family members, caregivers, or other providers might be more helpful in providing a detailed description of the person's sleep pattern. Moreover, individuals with severe TBI who acknowledge their sleep difficulties might not recognize how poor sleep affects their daytime functioning. In such cases, supplementing self-report sleep measures with reports by a significant other should be considered by clinicians or researchers. Alternatively, individuals with milder TBI might be more aware of changes in their sleep since the injury, and are more likely to report these changes.⁴⁷ Studies have shown that people with mild TBI are more likely to report on a range of symptoms.^{48,49} As discussed earlier, some researchers observed symptom magnification in the mild TBI group.^{2,5} We therefore propose that one's level of awareness or insight may not necessarily be a function of global cognitive functioning post-TBI, but may be more related to the state of frontal-executive functioning^{50,51}; however, this dimension was not studied in the literature discussed in this review. Furthermore, depressive symptoms, pain, and personality disorders that are pre-morbid or occur post-injury can contribute to diminished coping abilities, possibly leading to negative perceptions of sleep quality.^{52,53} In this case, the recommended measures would have more concrete domains that comprehensively assess the different aspects of sleep quality pre- and post-injury, and explore the complex symptom interactions in TBI patients, such as pain, psychological profile, the effect of medications, and comorbid medical conditions.

An appropriate tool always considers the characteristics of the study/clinical population to be assessed. However, some of the measures did not capture the unique characteristics of people with TBI. In the ESS, for example, some items refer to the probability of falling asleep during driving or sitting in a public place (e.g., theater or meeting), activities which may not be relevant to a person with TBI. Answering these items hypothetically may result in inaccurate scores.

Another example is the applicability of the generic MOS sleep scale, as the lack of items assessing the use of sleep medication and those related to leg movements, as well as the inability of some respondents to complete all items, highlight the need for precaution in its application. When researchers utilized the MEQ, they felt that concepts might have been too abstract for cognitively impaired persons; furthermore, patients might require a high level of cognitive ability to think in terms of their "best-feeling rhythm" and picture how they might feel when asked to engage in exercise at certain times of the day.^{10,38} The SDQ and the BSIQ require significant cognitive and mental demand for completion due to the quantity of items. As for the SNS, patients might find it difficult to answer questions 4 and 5 (knee buckling and sagging of jaw during cataplexy) due to the likelihood of motor impairments related to the injury itself and not to a sleep disorder being screened for.

Thus, in order to ensure that a measure gathers unbiased information, researchers and clinicians must consider the following characteristics of TBI persons. First, the cognitive ability of the person with TBI to understand and respond to the items in the questionnaire must be considered. This is specifically relevant to participants with severe TBI. In such cases, the help of a significant other/caregiver will likely enhance the validity of the responses and accuracy in reporting on issues such as snoring, bruxism, periodic leg movements (PLM), sleep talking, etc. Second, measures with fewer response choices, more concrete items instead of Likert responses, and using visual analog scales might be more suitable. Third, the respondent's ability to recall information over a defined period of time is vital for consideration; measures with a shorter recall period are likely to produce more accurate responses. Fourth, the appropriateness of the measure's domains and items to the population being assessed is of great importance, as injury to the brain often results in considerable changes in functioning, such that certain physical and social activities referred to in the questionnaires designed for the general population might not be applicable to a disabled person. Finally, another feature that may impact responses is the sensitivity of the issue being addressed in the question. For example, a participant may not honestly report on the probability of events such as "falling asleep while stopped for a few minutes in traffic", fearing the consequences of the admission. The discussion of the issues encountered with use of self-report measures in the TBI population in this review is restricted, as none of the included studies reported on skipped and/or missing items. In future studies, researchers should consider omission of irrelevant or non-applicable items within the utilized self-report measures and report on such occurrences to provide knowledge users with information to weigh the advantages and disadvantages of use of a particular measure in the TBI population.

In this context, prior to the utilization of a self-report measure, it is important to assess its validity, reliability, and responsiveness in the TBI population. To date, only two measures have been partially tested (e.g., concurrent validity) in the population of interest.^{19,30} This poses a risk to TBI researchers and clinicians regarding interpretation of the results and their ability to rely on self-report scores when assessing sleep post-TBI. While self-perception is unique and important, the accuracy of self-reporting remains a challenge. The current view of many researchers in the field of TBI is that objective and subjective measures should be utilized together in clinical settings and research studies in the TBI population.^{2,8,19,23,31}

Finally, when selecting a sleep assessment tool from those available, careful consideration of which domains the measure will screen, diagnose, or monitor is a priority. In efficacy studies of treatment intervention, the following are considered most important: treatment responsiveness, a continuous measurement scale, transparency of scoring, broad symptom coverage, overall summary scoring, and the timeframe of reporting. In drug efficacy

studies, special attention should be paid toward items regarding symptoms, especially if the medication has side effects resembling symptoms of sleep impairment (e.g., fatigue, sleepiness), because their inclusion in a measure will reduce the chances of demonstrating a treatment effect.⁵⁴ For observational studies focusing on population description or analyzing data to find risk factors, the main characteristic of a measure would be its diagnostic specificity, as classifying patients accurately is crucial (e.g., the instrument should be able to differentiate depression-related insomnia from psychological or primary insomnia⁵⁴). Given the number of confounders associated with poor sleep post-TBI, it is important to consider inclusion of additional measurements of comorbidities in order to prevent or minimize confounding effects. Of less importance are continuous measurement scaling and the transparency of scoring of the measure.

It is important to conclude our discussion by providing thoughts on the various applications of self-report sleep measures by researchers and clinicians. Clinicians are traditionally focused on sleep problem diagnosis and evaluation of symptoms, whereas researchers primarily concentrate on the determinants and consequences of poor sleep. Although standardized self-report measures can assist in clinical decision-making, they are rarely used in clinical practice, mainly as primary outcomes in clinical trials. The reasons for this gap between research and clinical practice is complex, and goes beyond the scope of this review; however, it may be related to the clinicians' lack of familiarity with self-report sleep measures available in the field, the large discrepancy observed between symptom burden rated by physician and patient, and most importantly, the lack of acceptance of the feasibility of self-report measures in assisting in clinical decision-making. However, a self-report sleep measure has the potential to directly promote patient-centered care if scales related to symptom burden, sleep function, and the impact of sleep on health outcomes (e.g., daytime functioning, community integration, quality of life) are incorporated into an instrument, in which case, the use of a self-report measure can support more informed clinical decision-making. For clinicians, the issues of sensitivity and practicality are attracting increasing attention. If a measure has just two categories (e.g., "yes" and "no"), it lacks sensitivity, as it cannot reflect fine distinctions in sleep quality or be used to record minor, but clinically significant changes. The practicality of the instrument, which is related to administration burden and analysis, as well as direct clinical interpretation of the scores (e.g., likelihood measures and visual scales preferable over numerical scores) are preferable in clinical practice. Measures such as the SDQ, BSIQ, and the DII may not suit a clinician, due to the large number of items impeding completion time. On the other hand, the PSQI, requiring less than 5 min to complete, can be administered to a patient in the waiting room. Furthermore, visual analog scales such as the DBAS and LSEQ do not require score calculation and can be of immediate use to the clinician when assessing their patient. Despite their potential benefits, before self-reported measures can be implemented into TBI clinical practice, research should focus on further evaluating the psychometric properties of measures developed for other study populations, which is a point of convergence for clinicians and researchers. This review serves as an introduction to the applicability of self-report sleep measures to the TBI population and is intended to complement the current clinical toolbox, with the goal of improving the quality of care provided to persons with brain injuries.

Limitations

Certain features of this review are open to debate. First, the language limitation in our literature search may not have identified all non-English measures. Second, all of the articles included in this

review were peer-reviewed and, as such, there is a publication bias. Third, not all studies that focused on fatigue were included in this review. To be consistent with our inclusion criteria, we incorporated only those in which researchers mainly focused on sleep, or attempted to discriminate fatigue from sleepiness. A further limitation applies to the way the data was presented. In order to be concise, purpose groups and the psychometric properties of each measure were not reported in great detail. Although we have attempted to find all relevant articles on the psychometric properties of the extracted measures, it is possible some studies were missed.

Finally, we excluded analysis of sleep diaries in this review, despite their frequency of use by researchers,^{6,7,27,28,30,35} and their potential in assessing sleep quality and quantity post-TBI. We decided this because few standardized sleep diaries are available (e.g., Karolinska sleep diary, Pittsburgh sleep diary), and none have been applied in the TBI population.

Furthermore, in the literature cited in this review, the sleep diary format varied. Scoring also varied, and results were generally applied toward a clinical diagnosis of insomnia and quantification of sleep and waking behavior over a specific period of time (usually 2–4 weeks). The strength of the instrument was its ability to prospectively depict sleep and daytime functioning over a period of time. However, the low return rates of diaries, response burden, possible impaired judgment, and common sleep state misperception in the TBI population warrants careful interpretation of results and accuracy.

Although this review was meant to shed light on how sleep dysfunction is currently measured in TBI research and clinical practice, and applied a broad search strategy, some existing measures were not included, as the studies in which they were utilized did not meet the inclusion criteria for this review (e.g., the study utilized an adjusted measure, focused on different topic). Despite these limitations, this review is the first to comprehensively assess self-report measures applied to evaluate sleep dysfunction in persons with TBI.

Conclusions

This systematic review demonstrates that although impaired sleep is highly prevalent in the TBI population, no instrument has been specifically developed for assessing sleep in adults with TBI. Moreover, despite a number of standardized measures utilized, only the PSQI and ESS have been validated against other sleep measures in a TBI sample. Currently, the field of TBI requires further testing of the existing self-report measures whose psychometric properties were described in other target populations, taking into account medication side effects, pain, anxiety, and depression, which may confound the outcome of sleep measures developed for the general population. With this, it is necessary and timely to design a new sleep instrument that would consider history, duration, and severity of sleep complaints and could be completed by a patient with the help of a family member/caregiver. This instrument should also report the consequences of the patient's poor sleep (e.g., impaired daytime functioning), include items to delineate the most common confounders, and feature items/scale for the most common sleep disorders. When and if a new measure is developed, before being used in research or clinical practice, the instrument should be assessed for its psychometric properties (e.g., reliability, validity, and responsiveness) in the TBI population across levels of injury severity. Even with a validated self-report measure, the utility of PSG should be considered for the diagnosis of specific sleep disorders (e.g., narcolepsy, sleep apnea, REM behavior disorder (RBD), PLM, erectile dysfunction after TBI, non-REM parasomnia, nocturnal seizures), which could not be fully diagnosed using only a self-report measure.

Practice points

- Of the 16 measures reviewed, none met the criteria for “well-established”, “approaching well-established” or “promising” in a TBI population. Across categories, many measures have demonstrated good psychometric properties in other study populations, providing an evidence base for their validation in TBI samples.
- Two studies reported on validity in TBI subjects. The PSQI was shown to have good concurrent validity when tested against sleep diary and clinical diagnoses of insomnia. When ESS and PSQI were compared with MSLT scores, no significant correlation was found.
- Several researchers stated under-/over-reported sleep disturbances by TBI participants and recommended self-report and objective instruments to be utilized together.
- Consideration of cognitive level and the relevance of the items in the choice of measure are important.
- Minimizing respondent burden by selecting shorter instruments may be more appropriate in TBI research and as a screening instrument in clinical practice.
- The input of the significant other/caregiver may enhance the validity of the self-report.
- When selecting a self-report sleep measure, the domains the measure will screen, diagnose or monitor should be considered.

Research agenda

- No instrument has been developed for assessing sleep post-TBI. Development of a new instrument which would consider specifics of the TBI population with a version for significant other/caregiver is a key for future direction.
- All but two measures have no data on psychometric properties in the TBI population. Further studies focusing of psychometric evaluation will provide greater insight into the utility of existing measures in TBI populations.
- The utility of polysomnography and actigraphy should be kept open in TBI population for the diagnosis of specific sleep disorders, which may not be fully captured by a self-report measure only.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.smrv.2013.02.001>.

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