



Published in final edited form as:

Arch Phys Med Rehabil. 2019 April ; 100(4 Suppl): S102–S109. doi:10.1016/j.apmr.2018.05.020.

Understanding health-related quality of life in caregivers of civilians and service members/veterans with traumatic brain injury: Establishing the reliability and validity of PROMIS Fatigue and Sleep Disturbance item banks

Noelle E. Carlozzi, Ph.D.¹, Phillip A. Ianni, M.A.¹, David S. Tulsy, Ph.D.², Tracey A. Brickell, D.Psych^{3,4,5}, Rael T. Lange, Ph.D.^{3,4,6}, Louis M. French, Psy.D.^{3,4,5}, David Cella, Ph.D.⁷, Michael A. Kallen, Ph.D.⁷, Jennifer A. Miner, M.B.A.¹, and Anna L. Kratz, Ph.D.¹

¹Department of Physical Medicine and Rehabilitation, University of Michigan; Ann Arbor, MI, USA

²Center for Assessment Research and Translation, Department of Psychological and Brain Sciences, University of Delaware, Newark, DE, USA

³Defense and Veterans Brain Injury Center, Walter Reed National Military Medical Center, Bethesda, Maryland, USA

⁴National Intrepid Center of Excellence, Walter Reed National Military Medical Center, Bethesda, Maryland, USA

⁵Uniformed Services University of the Health Sciences, Bethesda, Maryland, USA

⁶University of British Columbia, Vancouver, British Columbia, Canada

⁷Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

Abstract

Objective: To examine the reliability and validity of Patient Reported Outcomes Measurement Information System (PROMIS) measures of sleep disturbance and fatigue in TBI caregivers and to determine the severity of fatigue and sleep disturbance in these caregivers.

Design: Cross-sectional survey data collected through an online data capture platform.

Setting: Four rehabilitation hospitals and Walter Reed National Military Medical Center.

Address reprint requests to: Noelle E. Carlozzi, Ph.D., University of Michigan, Department of Physical Medicine & Rehabilitation, North Campus Research Complex, 2800 Plymouth Road, Building NCRC B14, Room G216, Ann Arbor, MI 48109-2800, Phone: (734) 763 – 8917, Fax: (734) 763-7186, carlozzi@med.umich.edu.

Disclaimer:

The identification of specific products or scientific instrumentation does not constitute endorsement or implied endorsement on the part of the author, DoD, or any component agency. While we generally exercise reference to products companies, manufacturers, organizations etc. in government produced works, the abstracts produced and other similarly situated research presents a special circumstance when such a product inclusions become an integral part of the scientific endeavor.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Participants: Caregivers (N=560) of civilians (n=344) and service member/veterans (n=216) with TBI.

Intervention: Not Applicable

Main Outcome Measures: PROMIS sleep and fatigue measures administered as both computerized adaptive tests (CATs) and 4-item short forms (SFs).

Results: For both samples, floor and ceiling effects for the PROMIS measures were low (<11%), internal consistency was very good (all alphas > 0.80), and test-retest reliability was acceptable (all $r > 0.70$ except for the fatigue CAT in the service member/veteran sample $r=0.63$). Convergent validity was supported by moderate correlations between the PROMIS and related measures. Discriminant validity was supported by low correlations between PROMIS measures and measures of dissimilar constructs. PROMIS scores indicated significantly worse sleep and fatigue for those caring for someone with high levels versus low levels of impairment.

Conclusions: Findings support the reliability and validity of the PROMIS CAT and SF measures of sleep disturbance and fatigue in caregivers of civilians and service members/veterans with TBI.

Keywords

PROMIS; sleep; fatigue; validity; reliability; caregiver; informal caregiver; traumatic brain injury

Traumatic brain injury (TBI) is often associated with long-term health problems, including difficulties with physical, behavioral, and/or cognitive functioning, especially when injuries are moderate-to-severe in nature.¹⁻³ For persons with TBI that require support, this caregiving role can be demanding, time-consuming, emotionally draining, and can greatly impact quality of life.⁴⁻¹⁸ While some research suggests that caregivers (in general) are at greater risk for health problems (compared to non-caregivers),^{19,20} the nature of the health problems among caregivers of persons with TBI are less well-known.

Recent evidence in caregivers of civilians with TBI,^{4,21,22} as well as in caregivers of service members/veterans (SMVs) with TBI,^{23,24} suggests that sleep difficulties and fatigue are common. Approximately 60% of caregivers of people with TBI report changes in sleep pattern.^{25,26} These findings are consistent with previous research suggesting that caregivers have worse sleep quality than non-caregivers.²⁷⁻³⁰

The broader caregiver literature proposes a model for sleep that posits that caregivers' health is negatively affected by not getting enough sleep (sleep deprivation) and fragmented sleep (sleep disruption).³¹ In this model, sleep deprivation and sleep disruption lead to sleep loss, which in turn results in worse physical, cognitive/behavioral (including fatigue), mental, and social health. While the precise cause of the sleep disturbance reported by caregivers of individuals with TBI is unknown, caregivers of individuals with dementia have been shown to have sleep problems secondary to the nocturnal problems among people with dementia.³² Since individuals with TBI have similar nocturnal problems, it is reasonable to speculate that similar issues are encountered by caregivers of people with TBI. Many individuals with TBI require round-the-clock care, which can deprive caregivers of sleep.³³ Sleep difficulties^{25,26} and sleep disorders^{34,35} are also much more common among individuals with TBI than the

general population. These sleep problems (in the person with TBI), likely contribute to sleep disruption among their caregivers.

Caregivers of people with TBI may be especially vulnerable to problems with sleep and fatigue. Over one-third of caregivers of people with TBI have pre-existing (pre-injury) emotional distress^{36,37} which may predispose them to sleep problems. Also, high levels of perceived stress,³⁸ fatigue, pain, anxiety, depression, onset of new health conditions, and increased rates of clinically significant emotional difficulties^{4,6-9,11-18,39-48} likely increase the risk that caregivers will experience sleep problems. In fact, rates of emotional distress in caregivers of people with TBI are significantly higher than in other clinical caregiving populations (e.g., caregivers of people with mobility impairments or developmental intellectual disabilities).^{49,50}

To better understand sleep and fatigue in caregivers of people with TBI, a well-validated measure is needed to provide a comprehensive assessment of the impact that sleep and fatigue have on the health-related quality of life (HRQOL) of these individuals. The purpose of this study was two-fold. First, we examined Patient-Reported Outcome Measurement Information System (PROMIS) Sleep Disturbance and PROMIS Fatigue in caregivers of civilians and SMVs with TBI to establish reliability and validity of these new measures. Second, we compared sample scores to population norms in order to determine the severity of fatigue and sleep disturbance in these caregivers.

Methods

Participants

We recruited 560 participants who were caregivers of civilians and SMVs (sample details provided in Carlozzi et al., this issue⁵¹). Eligible caregivers needed to be 18 years old and able to read and understand English. Caregivers were required to be providing some form of care (emotional support, physical assistance, or financial assistance) to an individual with a medically documented TBI who was >1 year post-injury (i.e., those caring for an individual still in the acute stage of recovery were not eligible⁵²⁻⁶³). For the caregivers of civilians, the individual with TBI also had to meet TBI model system inclusion criteria for a complicated mild, moderate or severe TBI.⁶⁴ Data was collected in accordance with the local site institutional review boards and participants provided consent prior to participation. Approximately three weeks after the initial study visit, 145 caregivers completed a retest.

Measures

Two PROMIS measures were administered: Sleep Disturbance⁶⁵ (perceptions of sleep quality; perceived difficulties with getting to sleep or staying asleep; and adequacy of and satisfaction with sleep) and Fatigue⁶⁵ (a sense of exhaustion that decreases one's ability to carry out daily activities). PROMIS measures were administered as computer adaptive tests (CATs) plus standard 4-item Short Forms (SFs). Both the CAT and SFs of the PROMIS measures were scaled on a T-score metric (i.e., M=50, SD=10); a higher score represents worse physical health. The reliability and validity of both of these measures has been established in other clinical populations.⁶⁶⁻⁷² Clinical cut scores exist for patients with

cancer^{68,73} and rheumatic diseases.⁷⁴ Minimally important differences are available for patients undergoing anterior cervical spine surgery⁷⁰ or with lumbar degenerative disease.⁷¹ Responsiveness has been demonstrated for both measures for spinal surgery⁷¹ and cancer treatment,⁷⁵ and for acupuncture (Sleep Disturbance only).⁷⁶

Generic HRQOL was measured using the RAND-12 Health Status Inventory.⁷⁷ The RAND-12 is a 12-item self-report measure in the public domain that assesses physical health and mental health; mental health includes one fatigue/vitality item. Scores range from 0 (low health) to 100 (highest level of health); administration takes ~5 minutes. Previous studies of the RAND-12 have demonstrated satisfactory reliability and validity.^{78–81}

We measured caregiver burden using two scales: the modified Caregiver Appraisal Scale (CAS)⁸² and the Zarit Burden Interview (ZBI).⁸³ The 35-item CAS measures perceived burden, caregiver relationship satisfaction, caregiving ideology, and caregiving mastery,⁸⁴ with higher scores indicating better functioning. Reliability and validity of this measure have been established.^{84–86} The ZBI⁸³ is a 22-item scale that measures caregiver burden. Total score ranges from 0 (low burden) to 88 (high burden). The ZBI offers literature-based evidence to support its reliability and validity;^{86–89} cut-scores have been established for the ZBI for identifying caregivers at risk for depression.⁹⁰

The Mayo-Portland Adaptability Inventory-Fourth Edition (MPAI-4)⁹¹ is a 35-item measure used to assess caregiver impressions of the functional ability of the person with TBI. It is scored on a T-score metric (M=50, SD=10); higher scores indicate lower functioning and score >60 suggest severe limitations in functioning for significant other ratings.⁹² Administration time is ~5–10 minutes. Previous studies indicate that the MPAI-4 has good reliability and validity.^{93–97}

Data Analysis

Assessment of data skewness and kurtosis indicated that the data were normally distributed and appropriate for parametric analyses.

Reliability.—Two forms of reliability were calculated: internal consistency reliability and test-retest reliability. Cronbach's alpha was calculated for all SFs and IRT-based internal consistency was calculated for all CATs to determine internal consistency reliability; minimal acceptable reliability was specified as 0.70.^{98,99} Test-retest reliability was calculated for those with repeat testing; the minimum test-retest reliability criterion was 0.70.^{98,99}

Floor and Ceiling Effects.—Ceiling effects represent the percentage of participants who had the highest possible scores on a given scale or subscale. Similarly, floor effects represent the percentage of participants who had the lowest possible scores on a given scale or subscale. For the CATs, floor and ceiling effects were calculated by dividing the raw CAT scores by the number of items administered (a score of 1 was a "ceiling effect" and a score of "5" was a "floor effect" for CATs). Acceptable floor and ceiling rates were 20%.^{100,101}

Administration times.—To establish feasibility for the administration of these measures, we examined timing data for both CAT and SF versions of the PROMIS measures. Start and stop times for each item were recorded electronically.

Convergent and Discriminant Validity.—To evaluate convergent and discriminant validity of the PROMIS measures, we examined correlations between similar and dissimilar traits.¹⁰² Strong correlations ($r > 0.6$) between scores from measures of the same trait were interpreted as being good evidence for convergent validity.¹⁰³ In contrast, weak correlations ($r < 0.3$) between scores of different traits were interpreted as evidence for discriminant validity.¹⁰³

Known groups validity.—We divided the participants into two groups, based on their MPAI-4 derived assessment of the individual with TBI: T scores less than 60 were considered “high functioning” and T scores greater than or equal to 60 were considered “low functioning.” We chose this cutoff because T-scores above 60 suggest severe limitations in functioning.⁹² For each PROMIS measure, comparisons were then made between low and high functioning groups using independent sample *t*-tests. We hypothesized that caregivers of high functioning individuals would rate their own sleep/fatigue as being better than those who cared for low functioning individuals.

Impairment Rates.—We examined clinical impairment rates (participants whose scores were >1 SD worse than the PROMIS normative sample mean of 50) to determine if caregivers of individuals with TBI were at greater risk than the general population for physical health impairments. According to the normal curve, 16% of the scores are expected to fall 1 SD below the mean (i.e., representing being impaired); therefore, impairment rates exceeding 16% would be judged as having greater impairment than might be expected compared to demographically comparable peers.¹⁰⁴

Missing Data.—For participants who had a small amount of missing data ($<10\%$ of items), scores were imputed using expectation maximization.¹⁰⁵ This method was chosen because it has been shown to be relatively unbiased compared to other common methods, such as mean substitution and regression.¹⁰⁶ Data were imputed for $n=39$ participants on the MPAI-4 and $n=15$ on the CAS. Participants who had larger amounts of missing data, or had no data for the entire scale, were removed from the dataset ($n=2$).

Results

Participants

Detailed descriptive data for both the civilian- and SMV samples are provided in Carlozzi et al..⁵¹ Briefly, caregivers of civilians were older ($M=51.6$ years of age; $SD=14.0$) than caregivers of SMVs with TBI ($M=37.2$ years of age; $SD=8.6$), $t(555.94)=15.04$, $p<.01$, and they were more likely to be caring for someone that was older ($M=42.3$ years of age, $SD=14.6$), than the caregivers of the SMVs ($M=37.1$ years of age, $SD=7.5$; $t(535.41)=5.56$, $p<.01$). Caregivers of SMVs had a higher proportion of women (98.1%), than those of civilians (78%), $\chi^2(1)=44.74$, $p<.001$; they also were more likely to be married (93%) relative to caregivers of civilians (36.6%; $\chi^2(1)=37.74$, $p<.001$). The groups did not differ

for time providing care, $t(513.244)=-.82, p=.41$. With regard to TBI severity, 56.1% were classified as severe, 20.9% moderate, and 17.7% complicated mild (5.2% were of unknown severity) for the caregivers of individuals with civilian TBI. For those caregivers of SMVs with TBI, 17.3% were uncomplicated mild, 1.9% were complicated mild, 1.4% were moderate, 1.4% were severe, 14.9% were TBI equivocal mild TBI, 1.4% were unknown, and 1.4% were penetrating (severity data was not available for 61.3% of this sample). Since these individuals were recruited from the community, it can be reasonably estimated that much of this sample (i.e., >80%) would be classified as mild TBI (according to existing prevalence rates¹⁰⁷). Regardless of the reported TBI severity for each of these groups, caregivers of SMVs were also more likely to be caring for an individual that they perceived to be low functioning (53.0%), relative to their civilian caregiver counterparts (12.3%; $\chi^2(1)=74.49, p<.001$).

Reliability

All of the scales demonstrated good internal consistency reliability (i.e. they met or exceeded the suggested minimum level of Cronbach's alpha or IRT-based reliability of 0.70, see Table 1). Test-retest reliability was generally acceptable for Fatigue in both the civilian sample (CAT: $r=.78$, SF: $r=.76$) and acceptable for the SF ($r=.70$) in the SMV sample; the reliability was low for the Fatigue CAT in the SMV sample ($r=.63$). Test-retest reliability was good for Sleep Disturbance in the civilian sample (CAT: $r=.86$, SF: $r=.85$) and the SMV sample (CAT: $r=.80$, SF: $r=.79$).

Floor and Ceiling Effects

Floor and ceiling effects for each PROMIS measure and administration format are shown in Table 1. In both samples, both floor effects and ceiling effects were lower for the CATs than the SFs for both fatigue and sleep disturbance. All were within acceptable limits.

Administration Times

Overall CAT and SF administration times were brief (Table 1), ranging from 24–33 seconds for the civilian sample, and 16–39 seconds for the SMV sample.

Convergent and Discriminant Validity

Correlations supporting convergent and discriminant validity are reported in Table 2. With regard to convergent validity, the two PROMIS Physical Health measures were moderately correlated with each other. The correlations between both PROMIS measures and the Rand-12 MHC (which includes an item about fatigue/vitality) were also moderate, providing further support for convergent validity. Correlations with physical health were small, supporting discriminant validity. Discriminant validity was also supported by negligible to small correlations between the two measures of Physical Health and the other three subscales of the CAS.

Known Groups Validity

Known-groups analyses compared scores on Fatigue and Sleep Disturbance for each group identified by the MPAI-4 (low and high functioning; Table 3). Caregivers of high

functioning individuals had significantly lower Fatigue and Sleep Disturbance scores, generally about ½ of a standard deviation lower, compared to caregivers of low-functioning individuals.

Impairment Rates

Impairment rates for caregivers of low functioning civilians with TBI were elevated relative to the general population, as were impairment rates for caregivers of both high and low functioning SMVs with TBI (Table 3). Rates of Sleep Disturbance and Fatigue for caregivers of high functioning civilians with TBI were comparable to that of the general population (Table 3).

Discussion

For caregivers of people with TBI, well-validated patient reported outcomes (PRO) measures that assess self-reported sleep or fatigue have been sorely needed. This study provides support for the reliability and validity of the PROMIS measures of Fatigue and Sleep Disturbance in caregivers of people with TBI.

Cronbach's alpha for PROMIS Sleep Disturbance and Fatigue were generally higher than or equivalent to other measures of physical function and HRQOL in caregivers of both civilians and SMVs with TBI. Furthermore, the CAT administration of the PROMIS measures was generally superior to the associated calibrated SF (as evidenced by fewer floor and ceiling effects and greater internal consistency reliability). In addition, the administration times for both CAT and SF administrations were generally 30 seconds or less per administration, highlighting the brevity of these new measures.

Convergent and discriminant validity of the PROMIS Sleep Disturbance and Fatigue measures were also supported by our findings. Specifically, convergent validity was supported by moderate associations between the PROMIS measures, as well as between the PROMIS measures and a composite score of mental health that included an item about vitality/fatigue. Furthermore, the moderate correlations between the sleep/fatigue measures and mental health are consistent with published findings supporting a well-established relationship between mental health and sleep/fatigue in other caregiver populations.^{29,108–111} In addition, discriminant validity was supported by smaller associations between the PROMIS measures and other measures of caregiver burden and HRQOL. This pattern of findings was consistent with our proposed hypotheses and provides support for the validity of PROMIS in caregivers of civilians and SMVs with TBI.

As expected, we also found that caregivers of individuals that were low functioning had more problems with sleep disturbance and fatigue than those caregivers of individuals that were high-functioning TBI for both the civilian and SMV samples. Furthermore, clinical impairment rates were higher for caregivers of those that were low functioning, relative to those that were caring for individuals that were high functioning (for both groups). In addition, for caregivers of SMVs, impairment rates were elevated regardless of the level of functioning of the SMV. We hypothesize that this may be due to the high rates of other comorbid clinical conditions commonly reported for these SMVs¹¹² (not assessed as a part

of this study). Elevated impairment rates are consistent with the existing literature, which suggests that approximately 60% percent of caregivers of persons with TBI report changes in sleep patterns.^{25,26} These findings are consistent with qualitative work in caregivers of TBI that indicate these individuals experience significant difficulties with sleep.^{4,21} Together, these findings support construct validity of these PROs in caregivers of civilians or SMVs with TBI and suggest that these measures may be especially relevant for caregivers of SMVs with TBI.

Study Limitations

This study relies solely on self-report data and did not include any objective assessments of sleep. Future research should focus on understanding how this PRO data relates to objective sleep measures. In addition, caregivers were primarily Caucasian, women, and spouses of the person with the TBI, thus generalizability is somewhat limited with regard to racial/ethnic minorities, male caregivers and caregivers that are parents or relations other than spouses. Future work could also focus on an examination of the overall intensity and duration of caregiver commitment, available social support for the caregiver, and other caregiver-specific factors (e.g., overall health status, occupation). Medical record documentation for injury severity was only available for 40% of the SMV sample, precluding our ability to examine the impact of TBI severity on analyses. Future research is needed to evaluate how TBI severity, as well as objective measures of functioning ability of the person with the TBI, affect caregiver HRQOL. The test-retest reliability time frame of 3 weeks was longer than what is typical of test-retest reliability, especially given that sleep and fatigue are likely to fluctuate over the course of a three-week time frame. Thus test-retest correlations are likely less robust than what might be expected given a shorter time frame. Future work is needed to establish responsiveness to change data in caregivers (including establishing minimal important differences for these measures). Also, more work is needed to understand the differences that were observed between caregivers of civilians and those of SMVs, including more consideration of TBI severity and functional capacity (mentioned above), as well as the influence that comorbid clinical conditions have on HRQOL for persons with TBI.

Conclusions

PROMIS Sleep Disturbance and Fatigue measures appear to provide brief, reliable, and valid assessments of physical health for caregivers of civilians and SMVs with TBI. Furthermore, these measures are able to differentiate between individuals that are caring for individuals with TBI that are low versus high functioning. Additional work is still needed to examine change over time and to determine the clinical utility of these measures. Ultimately, these measures fill a significant measurement gap for caregivers of people with TBI.

Acknowledgements:

Work on this manuscript was supported by the National Institutes of Health (NIH)- National Institute of Nursing Research (R01NR013658), the National Center for Advancing Translational Sciences (UL1TR000433), and the Defense and Veterans Brain Injury Center (DVBIC). We thank the investigators, coordinators, and research associates/assistants who worked on this study, the study participants, and organizations who supported recruitment

efforts. The University of Michigan Research Team would also like to thank the Hearts of Valor and the Brain Injury Association of Michigan for assistance with community outreach for recruitment efforts at this site.

TBI-CareQOL Site Investigators and Coordinators: Noelle Carlozzi, Anna Kratz, Amy Austin, Mitchell Belanger, Micah Warschusky, Siera Goodnight, Jennifer Miner (University of Michigan, Ann, Arbor, MI); Angelle Sander (Baylor College of Medicine and TIRR Memorial Hermann, Houston, TX), Curtisa Light (TIRR Memorial Hermann, Houston, TX); Robin Hanks, Daniela Ristova-Trendov (Wayne State University/Rehabilitation Institute of Michigan, Detroit, MI); Nancy Chiaravalloti, Dennis Tirri, Belinda Washington (Kessler Foundation, West Orange, NJ); Tracey Brickell, Rael Lange, Louis French, Rachel Gartner, Megan Wright, Angela Driscoll, Diana Nora, Jamie Sullivan, Nicole Varbedian, Johanna Smith, Lauren Johnson, Heidi Mahatan, Mikelle Mooney, Mallory Frazier, Zoe Li, and Deanna Pruitt (Walter Reed National Military Medical Center/Defense and Veterans Brain Injury Center, Bethesda, MD)

List of abbreviations:

CAS	Caregiver Appraisal Scale
CAT	Computer Adaptive Test
HRQOL	Health-Related Quality of Life
MPAI-4	Mayo-Portland Adaptability Inventory-Fourth Edition
PRO	Patient-Reported Outcome
PROMIS	Patient-Reported Outcomes Measurement Information System
SF	Short Form
SMV	Service Member/Veteran
WRNMMC	Walter Reed National Military Medical Center
TBI	Traumatic Brain Injury
ZBI	Zarit Burden Inventory

References

1. Langlois JA, Rutland-Brown W, Wald MM. The epidemiology and impact of traumatic brain injury: a brief overview. *J Head Trauma Rehabil.* 2006;21(5):375–378. [PubMed: 16983222]
2. Hoofien D, Gilboa A, Vakil E, Donovick PJ. Traumatic brain injury (TBI) 10–20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Inj.* 2001;15(3):189–209. [PubMed: 11260769]
3. Dijkers MP. Quality of life after traumatic brain injury: a review of research approaches and findings. *Arch Phys Med Rehabil.* 2004;85(4 Suppl 2):S21–35.
4. Jumisko E, Lexell J, Soderberg S. Living with moderate or severe traumatic brain injury: the meaning of family members' experiences. *J Fam Nurs.* 2007;13(3):353–369. [PubMed: 17641113]
5. Kreutzer JS, Gervasio AH, Camplair PS. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Injury.* 1994;8(3):197–210. [PubMed: 8004079]
6. Peters LC, Stambrook M, Moore AD, Esses L. Psychosocial sequelae of closed head injury: effects on the marital relationship. *Brain Injury.* 1990;4(1):39–47. [PubMed: 2297599]
7. Wood RL, Yurdakul LK. Change in relationship status following traumatic brain injury. *Brain Injury.* 1997;11(7):491–501. [PubMed: 9210986]
8. Carlozzi NE, Brickell TA, French LM, et al. Caring for our wounded warriors: A qualitative examination of health-related quality of life in caregivers of individuals with military related

- traumatic brain injury. *Journal of rehabilitation research and development*. 2016;53(6):669–680. [PubMed: 27997672]
9. Kozloff R Networks of social support and the outcome from severe head injury. *Journal of Head Trauma Rehabilitation*. 1987;2:14–23.
 10. Livingston MG, Brooks DN, Bond MR. Patient outcome in the year following severe head injury and relatives' psychiatric and social functioning. *Journal of Neurology, Neurosurgery, and Psychiatry*. 1985;48(9):876–881.
 11. Hall KM, Karzmark P, Stevens M, Englander J, O'Hare P, Wright J. Family stressors in traumatic brain injury: A two-year follow-up. *Archives of Physical Medicine & Rehabilitation*. 1994;75(8): 876–884. [PubMed: 8053794]
 12. Panting A, Merry P. The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabilitation*. 1972;38:33–37.
 13. National Alliance for Caregiving. Caregivers of Veterans-Serving on the Homefront: Report of Study Findings. 2010 http://www.caregiving.org/data/2010_Caregivers_of_Veterans_FULLREPORT_WEB_FINAL.pdf Accessed April 3, 2018.
 14. Lester P, Peterson K, Reeves J, et al. The long war and parental combat deployment: effects on military children and at-home spouses. *J Am Acad Child Adolesc Psychiatry*. 2010;49(4):310–320. [PubMed: 20410724]
 15. Ruff RL, Ruff SS, Wang XF. Improving sleep: initial headache treatment in OIF/OEF veterans with blast-induced mild traumatic brain injury. *Journal of rehabilitation research and development*. 2009;46(9):1071–1084. [PubMed: 20437313]
 16. Taft CT, Schumm JA, Panuzio J, Proctor SP. An examination of family adjustment among Operation Desert Storm veterans. *J Consult Clin Psychol*. 2008;76(4):648–656. [PubMed: 18665692]
 17. Mansfield AJ, Kaufman JS, Marshall SW, Gaynes BN, Morrissey JP, Engel CC. Deployment and the use of mental health services among U.S. Army wives. *N Engl J Med*. 2010;362(2):101–109. [PubMed: 20071699]
 18. Jacobs HE. The Los Angeles Head Injury Survey: procedures and initial findings. *Arch Phys Med Rehabil*. 1988;69(6):425–431. [PubMed: 3132129]
 19. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*. 2003;129(6):946–972. [PubMed: 14599289]
 20. Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*. 1997;19(2):110–116. [PubMed: 9603685]
 21. Carlozzi NE, Kratz AL, Sander AM, et al. Health-related quality of life in caregivers of individuals with traumatic brain injury: development of a conceptual model. *Arch Phys Med Rehabil*. 2015;96(1):105–113. [PubMed: 25239281]
 22. Knight RG, Devereux R, Godfrey HP. Caring for a family member with a traumatic brain injury. *Brain Inj*. 1998;12(6):467–481.
 23. Carlozzi NE, Brickell TA, French LM, et al. Caring for our wounded warriors: A qualitative examination of health-related quality of life in caregivers of individuals with military-related traumatic brain injury. *Journal of Rehabilitation Research & Development*. 2016;53(6):669–680. [PubMed: 27997672]
 24. Saban KL, Griffin JM, Urban A, Janusek MA, Pape TLB, Collins E. Perceived health, caregiver burden, and quality of life in women partners providing care to Veterans with traumatic brain injury. *Journal of Rehabilitation Research & Development*. 2016;53(6):681–691. [PubMed: 27997670]
 25. Marsh NV, Kersel DA, Havill JA, Sleigh JW. Caregiver burden during the year following severe traumatic brain injury. *Journal of clinical and experimental neuropsychology*. 2002;24(4):434–447. [PubMed: 12187457]
 26. Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 6 months following severe traumatic brain injury. *Brain Inj*. 1998;12(3):225–238. [PubMed: 9547953]

27. Castro CM, Lee KA, Bliwise DL, Urizar GG, Woodward SH, King AC. Sleep patterns and sleep-related factors between caregiving and non-caregiving women. *Behav Sleep Med.* 2009;7(3):164–179. [PubMed: 19568966]
28. Fonareva I, Amen AM, Zajdel DP, Ellingson RM, Oken BS. Assessing sleep architecture in dementia caregivers at home using an ambulatory polysomnographic system. *J Geriatr Psychiatry Neurol.* 2011;24(1):50–59. [PubMed: 21320949]
29. McCurry SM, Logsdon RG, Teri L, Vitiello MV. Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment implications. *Sleep Med Rev.* 2007;11(2):143–153. [PubMed: 17287134]
30. Smith MC, Ellgring H, Oertel WH. Sleep disturbances in Parkinson's disease patients and spouses. *J Am Geriatr Soc.* 1997;45(2):194–199. [PubMed: 9033518]
31. Lee KA. Impaired Sleep In: Carrieri-Kohlman V, Lindsey A, CM W, eds. *Pathophysiological phenomena in nursing: Human responses to illness.* St Louis, MO 2003:363–385.
32. Pollak CP, Perlick D. Sleep problems and institutionalization of the elderly. *J Geriatr Psychiatry Neurol.* 1991;4(4):204–210. [PubMed: 1789908]
33. Enright R, Friss L. *Employed caregivers of brain-impaired adults: An assessment of the dual role.* San Francisco, CA: Family Survival Project; 1987.
34. Mathias JL, Alvaro PK. Prevalence of sleep disturbances, disorders, and problems following traumatic brain injury: a meta-analysis. *Sleep Med.* 2012;13(7):898–905. [PubMed: 22705246]
35. Castriotta RJ, Murthy JN. Sleep disorders in patients with traumatic brain injury: a review. *CNS Drugs.* 2011;25(3):175–185. [PubMed: 21062105]
36. Sander AM, Sherer M, Malec JF, et al. Preinjury emotional and family functioning in caregivers of persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation.* 2003;84(2):197–203. [PubMed: 12601650]
37. Davis LC, Sander AM, Struchen MA, Sherer M, Nakase-Richardson R, Malec JF. Medical and psychosocial predictors of caregiver distress and perceived burden following traumatic brain injury. *J Head Trauma Rehabil.* 2009;24(3):145–154. [PubMed: 19461362]
38. Sander AM. Interventions for caregivers In: High M, Sander AM, Struchen MA, Hart KA, eds. *Rehabilitation for Traumatic Brain Injury.* New York: Oxford University Press; 2005:156–175.
39. Kreutzer JS, Gervasio AH, Camplair PS. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Inj.* 1994;8(3):197–210. [PubMed: 8004079]
40. Livingston MG, Brooks DN, Bond MR. Patient outcome in the year following severe head injury and relatives' psychiatric and social functioning. *J Neurol Neurosurg Psychiatry.* 1985;48(9):876–881. [PubMed: 4045482]
41. Bayen E, Jourdan C, Ghout I, et al. Objective and Subjective Burden of Informal Caregivers 4 Years After a Severe Traumatic Brain Injury: Results From the Paris-TBI Study. *J Head Trauma Rehabil.* 2016;31(5):E59–67.
42. Marsh NV, Kersel DA, Havill JH, Sleight JW. Caregiver burden at 1 year following severe traumatic brain injury. *Brain Inj.* 1998;12(12):1045–1059. [PubMed: 9876864]
43. Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Inj.* 2003;17(6):453–468. [PubMed: 12745702]
44. Ergh TC, Hanks RA, Rapport LJ, Coleman RD. Social support moderates caregiver life satisfaction following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology.* 2003;25(8):1090–1101. [PubMed: 14566583]
45. Coleman RD, Rapport LJ, Ergh TC, Hanks RA, Ricker JH, Millis SR. Predictors of driving outcome after traumatic brain injury. *Arch Phys Med Rehabil.* 2002;83(10):1415–1422. [PubMed: 12370878]
46. Mazlan M, Ghani S, Tan KF, Subramanian P. Life satisfaction and strain among informal caregivers of patients with traumatic brain injury in Malaysia. *Disability and Rehabilitation.* 2016;38(22):2198–2205.
47. Manskow US, Sigurdardottir S, Roe C, et al. Factors Affecting Caregiver Burden 1 Year After Severe Traumatic Brain Injury: A Prospective Nationwide Multicenter Study. *Journal of Head Trauma Rehabilitation.* 2015;30(6):411–423. [PubMed: 25119652]

48. Sander AM, Maestas KL, Clark AN, Havins WN. Predictors of Emotional Distress in Family Caregivers of Persons with Traumatic Brain Injury: A Systematic Review. *Brain Impairment*. 2013;14(1):113–129.
49. Dillahunt-Aspillaga C, Jorgensen-Smith T, Ehlke S, Sosinski M, Monroe D, Thor J. Traumatic Brain Injury: Unmet Support Needs of Caregivers and Families in Florida. *Plos One*. 2013;8(12).
50. Degeneffe CE, Chan F, Dunlap L, Man D, Sung C. Development and Validation of the Caregiver Empowerment Scale: A Resource for Working With Family Caregivers of Persons With Traumatic Brain Injury. *Rehabilitation Psychology*. 2011;56(3):243–250. [PubMed: 21787096]
51. Carlozzi NE, Kallen MA, Hanks R, et al. The TBI-CareQOL Measurement System: Development and validation of health-related quality of life measures for caregivers of individuals with civilian- and military-related traumatic brain injury Under Review.
52. Dikmen S, Corrigan JD, Levin HS, Machamer J, Stiers W, Weisskopf MG. Cognitive outcome following traumatic brain injury. *Journal of Head Trauma Rehabilitation*. 2009;24(6):430–438. [PubMed: 19940676]
53. Dikmen S, Machamer JE, Winn HR, Temkin NR. Neuropsychological Outcome at 1-Year Post Head-Injury. *Neuropsychology*. 1995;9(1):80–90.
54. Dikmen S, Mclean A, Temkin N. Neuropsychological and Psychosocial Consequences of Minor Head-Injury. *Journal of Neurology Neurosurgery and Psychiatry*. 1986;49(11):1227–1232.
55. Dikmen S, Reitan RM, Temkin NR. Neuropsychological recovery in head injury. *Archives of Neurology*. 1983;40(6):333–338. [PubMed: 6847436]
56. Burns AS, Marino RJ, Flanders AE, Flett H. Clinical diagnosis and prognosis following spinal cord injury. *Handb Clin Neurol*. 2012;109:47–62. [PubMed: 23098705]
57. Ditunno JF, Jr., Stover SL, Freed MM, Ahn JH. Motor recovery of the upper extremities in traumatic quadriplegia: a multicenter study. *Arch Phys Med Rehabil*. 1992;73(5):431436.
58. Waters RL, Yakura JS, Adkins RH, Sie I. Recovery following complete paraplegia. *Arch Phys Med Rehabil*. 1992;73(9):784–789. [PubMed: 1514883]
59. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following complete tetraplegia. *Arch Phys Med Rehabil*. 1993;74(3):242–247. [PubMed: 8439249]
60. Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following incomplete paraplegia. *Arch Phys Med Rehabil*. 1994;75(1):67–72. [PubMed: 8291966]
61. Waters RL, Adkins R, Yakura J, Sie I. Donal Munro Lecture: Functional and neurologic recovery following acute SCI. *J Spinal Cord Med*. 1998;21(3):195–199. [PubMed: 9863928]
62. Jorgensen HS, Nakayama H, Raaschou HO, Vive-Larsen J, Stoier M, Olsen TS. Outcome and time course of recovery in stroke. Part II: Time course of recovery. The Copenhagen Stroke Study. *Arch Phys Med Rehabil*. 1995;76(5):406–412. [PubMed: 7741609]
63. Jorgensen HS, Nakayama H, Raaschou HO, Vive-Larsen J, Stoier M, Olsen TS. Outcome and time course of recovery in stroke. Part I: Outcome. The Copenhagen Stroke Study. *Arch Phys Med Rehabil*. 1995;76(5):399–405. [PubMed: 7741608]
64. Corrigan JD, Cuthbert JP, Whiteneck GG, et al. Representativeness of the Traumatic Brain Injury Model Systems National Database. *Journal of Head Trauma Rehabilitation*. 2012;27(6):391–403. [PubMed: 21897288]
65. Cella D, Riley W, Stone A, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology*. 2010;63(11):1179–1194. [PubMed: 20685078]
66. Yu L, Buysse DJ, Germain A, et al. Development of short forms from the PROMIS sleep disturbance and Sleep-Related Impairment item banks. *Behav Sleep Med*. 2011;10(1):6–24. [PubMed: 22250775]
67. Buysse DJ, Yu L, Moul DE, et al. Development and validation of patient-reported outcome measures for sleep disturbance and sleep-related impairments. *Sleep*. 2010;33(6):781–792. [PubMed: 20550019]
68. Leung YW, Brown C, Cosio AP, et al. Feasibility and diagnostic accuracy of the Patient-Reported Outcomes Measurement Information System (PROMIS) item banks for routine surveillance of

- sleep and fatigue problems in ambulatory cancer care. *Cancer*. 2016;122(18):2906–2917. [PubMed: 27351521]
69. Quach CW, Langer MM, Chen RC, et al. Reliability and validity of PROMIS measures administered by telephone interview in a longitudinal localized prostate cancer study. *Quality of Life Research*. 2016;25(11):2811–2823. [PubMed: 27240448]
 70. Purvis TE, Andreou E, Neuman BJ, Riley LH, 3rd, Skolasky RL. Concurrent Validity and Responsiveness of PROMIS Health Domains Among Patients Presenting for Anterior Cervical Spine Surgery. *Spine (Phila Pa 1976)*. 2017;42(23):E1357–E1365. [PubMed: 28742757]
 71. Purvis TE, Neuman BJ, Riley LH, 3rd, Skolasky RL. Discriminant Ability, Concurrent Validity, and Responsiveness of PROMIS Health Domains Among Patients With Lumbar Degenerative Disease Undergoing Decompression With or Without Arthrodesis. *Spine (Phila Pa 1976)*. 2018.
 72. Amtmann D, Bamer AM, Kim J, Chung H, Salem R. People with multiple sclerosis report significantly worse symptoms and health related quality of life than the US general population as measured by PROMIS and NeuroQoL outcome measures. *Disabil Health J*. 2018;11(1):99–107. [PubMed: 28442320]
 73. Jensen RE, Potosky AL, Moinpour CM, et al. United States Population-Based Estimates of Patient-Reported Outcomes Measurement Information System Symptom and Functional Status Reference Values for Individuals With Cancer. *J Clin Oncol*. 2017;35(17):1913–1920. [PubMed: 28426375]
 74. Nagaraja V, Mara C, Khanna PP, et al. Establishing clinical severity for PROMIS((R)) measures in adult patients with rheumatic diseases. *Quality of Life Research*. 2018;27(3):755–764. [PubMed: 28983738]
 75. Jensen RE, Moinpour CM, Potosky AL, et al. Responsiveness of 8 Patient-Reported Outcomes Measurement Information System (PROMIS) measures in a large, community-based cancer study cohort. *Cancer*. 2017;123(2):327–335. [PubMed: 27696377]
 76. Victorson D, Beaumont JL, Mahadevan R, et al. Acupuncture-Related Quality of Life Changes Using PROMIS Computer Adaptive Tests in a Pragmatic Trial with Oncology and General Integrative Medicine Patients: The Role of Baseline Acupuncture Expectations. *J Altern Complement Med*. 2016;22(10):778–787. [PubMed: 27467506]
 77. Hays RD, Sherbourn CD, Mazel R. User's manual for the Medical Outcomes Study (MOS) core measures of health-related quality of life. Santa Monica, CA: RAND corporation; 1995.
 78. Feeny D, Farris K, Cote I, Johnson JA, Tsuyuki RT, Eng K. A cohort study found the RAND-12 and Health Utilities Index Mark 3 demonstrated construct validity in high-risk primary care patients. *Journal of Clinical Epidemiology*. 2005;58(2):138–141. [PubMed: 15680746]
 79. Johnson JA, Maddigan SL. Performance of the RAND-12 and SF-12 summary scores in type 2 diabetes. *Quality of Life Research*. 2004;13(2):449–456. [PubMed: 15085917]
 80. Maddigan SL, Feeny DH, Johnson JA, Investigators D. Construct validity of the RAND12 and Health Utilities Index Mark 2 and 3 in type 2 diabetes. *Quality of Life Research*. 2004;13(2):435–448. [PubMed: 15085916]
 81. Selim AJ, Rogers W, Fleishman JA, et al. Updated U.S. population standard for the Veterans RAND 12-item Health Survey (VR-12). *Quality of Life Research*. 2009;18(1):43–52. [PubMed: 19051059]
 82. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *Journal of gerontology*. 1989;44(3):P61–71. [PubMed: 2715587]
 83. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20(6):649–655. [PubMed: 7203086]
 84. Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, Sander AM. A multidimensional measure of caregiving appraisal: validation of the Caregiver Appraisal Scale in traumatic brain injury. *J Head Trauma Rehabil*. 2002;17(2):132–154. [PubMed: 11909511]
 85. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *Journal of gerontology*. 1989;44(3):P61–71. [PubMed: 2715587]
 86. Whalen KJ, Buchholz SW. The reliability, validity and feasibility of tools used to screen for caregiver burden: a systematic review. *JBI Libr Syst Rev*. 2009;7(32):1373–1430. 87. [PubMed: 27820461]

87. Hebert R, Bravo G, Preville M. Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging-Revue Canadienne Du Vieillessement*. 2000;19(4):494–507.
88. Seng BK, Luo N, Ng WY, et al. Validity and reliability of the Zarit Burden Interview in assessing caregiving burden. *Ann Acad Med Singapore*. 2010;39(10):758–763. [PubMed: 21063635]
89. Al-Rawashdeh SY, Lennie TA, Chung ML. Psychometrics of the Zarit Burden Interview in Caregivers of Patients With Heart Failure. *J Cardiovasc Nurs*. 2016;31(6):E21–E28. [PubMed: 27617563]
90. Schreiner AS, Morimoto T, Arai Y, Zarit S. Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging & Mental Health*. 2006;10(2):107–111. [PubMed: 16517485]
91. Malec JF, Kragness M, Evans RW, Finlay KL, Kent A, Lezak MD. Further psychometric evaluation and revision of the Mayo-Portland Adaptability Inventory in a national sample. *J Head Trauma Rehabil*. 2003;18(6):479–492. [PubMed: 14707878]
92. Malec J The Mayo-Portland Adaptability Inventory. The Center for Outcome Measurement in Brain Injury; 2005: <http://www.tbims.org/combi/mpai>. Accessed July 27, 2017.
93. Wilde EA, Whiteneck GG, Bogner J, et al. Recommendations for the use of common outcome measures in traumatic brain injury research. *Archives of Physical Medicine & Rehabilitation*. 2010;91(11):1650–1660 e1617. [PubMed: 21044708]
94. Kean J, Malec JF, Altman IM, Swick S. Rasch measurement analysis of the MayoPortland Adaptability Inventory (MPAI-4) in a community-based rehabilitation sample. *Journal of Neurotrauma*. 2011;28(5):745–753. [PubMed: 21332409]
95. Malec JF, Kean J, Altman IM, Swick S. Mayo-Portland adaptability inventory: comparing psychometrics in cerebrovascular accident to traumatic brain injury. *Archives of Physical Medicine & Rehabilitation*. 2012;93(12):2271–2275. [PubMed: 22743410]
96. Fortune DG, Walsh RS, Waldron B, et al. Changes in aspects of social functioning depend upon prior changes in neurodisability in people with acquired brain injury undergoing post-acute neurorehabilitation. *Frontiers in Psychology*. 2015;6:1368. [PubMed: 26441744]
97. Bohac DL, Malec JF, Moessner AM. Factor analysis of the Mayo-Portland Adaptability Inventory: Structure and validity. *Brain Injury*. 1997;11(7):469–482. [PubMed: 9210984]
98. Cohen J Statistical power analysis for the behavioral sciences (2nd edition). New York: Academic Press; 1988.
99. DeVellis R Scale development: Theory and applications. 4th ed. Los Angeles, CA: Sage; 2017.
100. Cramer D, Howitt DL. The Sage dictionary of statistics. Thousand Oaks, CA: Sage; 2004.
101. Andresen EM. Criteria for assessing the tools of disability outcomes research. *Archives of Physical Medicine & Rehabilitation*. 2000;81(12 Suppl 2):S15–20. [PubMed: 11128900]
102. Campbell DT, Fiske DW. Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin*. 1959;56(2):81–105. [PubMed: 13634291]
103. DeVellis RF. Classical test theory. *Medical Care*. 2006;44(11 Suppl 3):S50–59. [PubMed: 17060836]
104. Heaton RK, Miller SW, Taylor JT, Grant I. Revised comprehensive norms for an expanded Halstead-Reitan Battery: Demographically adjusted neuropsychological norms for African American and Caucasian adults. Lutz, FL: Psychological Assessment Resources, Inc.; 2004.
105. Dempster AP, Laird NM, Rubin DB. Maximum Likelihood from Incomplete Data Via Em Algorithm. *Journal of the Royal Statistical Society Series B-Methodological*. 1977;39(1):1–38.
106. Musil CM, Warner CB, Yobas PK, Jones SL. A comparison of imputation techniques for handling missing data. *West J Nurs Res*. 2002;24(7):815–829. [PubMed: 12428897]
107. DVBIC. DoD Worldwide Numbers for TBI. 2015; <http://dvbic.dcoe.mil/dod-worldwidenumbers-tbi>. Accessed 02/10, 2017.
108. Liu S, Li C, Shi Z, et al. Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of clinical nursing*. 2017;26(9–10):1291–1300. [PubMed: 27681477]

109. Peng HL, Chang YP. Sleep disturbance in family caregivers of individuals with dementia: a review of the literature. *Perspect Psychiatr Care*. 2013;49(2):135–146. [PubMed: 23557457]
110. Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C. Symptom experience of family caregivers of patients with cancer. *Oncology Nursing Forum*. 2008;35(2):E23–44. [PubMed: 19405245]
111. Berger AM, Parker KP, Young-McCaughan S, et al. Sleep wake disturbances in people with cancer and their caregivers: state of the science. *Oncology Nursing Forum*. 2005;32(6):E98–126. [PubMed: 16270104]
112. Lange RT, Brickell TA, Kennedy JE, et al. Factors influencing postconcussion and posttraumatic stress symptom reporting following military-related concurrent polytrauma and traumatic brain injury. *Arch Clin Neuropsychol*. 2014;29(4):329–347. [PubMed: 24723461]

Highlights:

- The PROMIS Sleep and Fatigue measures are both reliable and valid
- The PROMIS Sleep and Fatigue measures are clinically relevant for caregivers
- Caregivers of persons with brain injury have problems with sleep and fatigue

Table 1
Descriptive Information and Reliability Data for Self-Report Physical Health Measures

	N	Mean Score (SD)	Internal Consistency ^o	3 Week Test-Retest Reliability	% of the sample with floor effects	% of the sample with ceiling effects	Mean Administration Time (sec)	Mean Administration Time/#items
Civilian sample								
Fatigue CAT	335	51.83 (9.63)	.94	.78	0.0	1.2	32.45	7.43
Fatigue SF	337	51.33 (9.93)	.93	.76	0.9	10.7	23.81	5.95
Sleep Disturbance CAT	335	51.32 (9.44)	.92	.86	0.0	1.5	32.92	6.37
Sleep Disturbance SF	336	51.46 (8.63)	.84	.85	0.6	4.5	24.29	6.07
Military sample								
Fatigue CAT	208	58.30 (9.22)	.94	.63	0.8	0.0	38.94	9.23
Fatigue SF	208	58.04 (9.21)	.94	.70	5.8	1.4	19.63	4.90
Sleep Disturbance CAT	208	58.16 (9.53)	.92--	.80	0.8	0.0	22.50	4.25
Sleep Disturbance SF	208	57.23 (8.11)	.81	.79	6.3	1.0	15.98	3.99

Note.

* = higher scores = better functioning;

^o Cronbach 's alphas are reported for all measures EXCEPT the computer adaptive tests which are reported as marginal (i.e., item response theory based) reliabilities.

PROMIS = Patient Reported Outcomes Measurement Information System;

CAT = Computer Adaptive Test;

SF = 4-item Short-Form;

CAS = Caregiver Appraisal Scale;

MPAI-4 = Mayo-Portland Adaptability Inventory-Fourth Edition;

ZBI = Zarit Burden Inventory;

retest samples were 56 civilians, 91 military

Table 2.

Convergent and discriminant validity of the PROMIS Physical Health CATs

Measures (CATs)	Sleep Disturbance	RAND-12 Mental Health	RAND-12 Physical Health	----Discriminant validity----				
				Burden	Satisfaction	Ideology	Mastery	Zarit Burden Interview
Civilian sample								
Fatigue	.65**	-.67**	-.29**	-.54**	-.19**	-.05	-.24**	.54**
Sleep Disturbance	--	-.49**	-.22**	-.38**	-.16**	-.10	-.22**	.41**
Military sample								
Fatigue	.56**	-.51**	-.34**	-.55**	-.23**	.04	-.24**	.55**
Sleep Disturbance	--	-.41**	-.26**	-.36**	-.08	.09	-.16*	.31**

* p < .05,

** p < .01

Table 3

Known Groups Validity for PROMIS Physical Health CATs

PROMIS CATs	Caregiver of a High Functioning Individual (MPAI-4 <60)		Caregiver of a Low Functioning Individual (MPAI-4 >60)		<i>t</i>	<i>p</i>
	Mean (SD)	% Impaired*	Mean (SD)	% Impaired*		
Civilian sample	N = 293		N = 42			
Fatigue	51.20 (9.34)	17.1	56.27 (10.50)	40.5	3.24	.001
Sleep Disturbance	50.68 (9.35)	15.0	55.76 (8.92)	28.6	3.31	.001
Military sample	N = 104		N = 101			
Fatigue	56.02 (8.98)	32.7	60.53 (8.68)	53.5	3.66	<.001
Sleep Disturbance	56.22 (9.35)	32.7	60.22 (9.45)	43.6	3.05	.003

Note.

PROMIS = Patient Reported Outcome Measurement Information System;

CATs = Computer Adaptive Tests;

MPAI-4 = Mayo-Portland Adaptability Inventory – Fourth Edition;

* = impairment rates reflect individuals with T score > 60