HHS Public Access

Establishing the Factor Structure of a Health-Related Quality of Life Measurement System for Caregivers of Persons Living with Traumatic Brain Injury

Jason H. Raad, Ph.D.[1], **David Tulsky, Ph.D.**[2], **Rael T. Lange, Ph.D.**[3,4,5,6], **Tracey A. Brickell, Ph.D.**[3,4,5,7], **Angelle M. Sander, Ph.D.**[8,9], **Robin A. Hanks, Ph.D.**[10,11], **Louis French, Ph.D.**[3,4,7], **Jennifer Miner, MBA**[1], **Pamela Kisala, MA**[2], **Noelle E. Carlozzi, Ph.D.**[1]

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

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

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

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

[5]Contractor, Defense and Veterans Brain Injury Center, Silver Spring, Maryland, USA

[6]Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada

[7]Edward Hebert School of Medicine, Uniformed Services University of the Health Sciences, Bethesda, Maryland, USA

[8]H. Ben Taub Department of Physical Medicine and Rehabilitation, Baylor College of Medicine & Harris Health System, Houston, TX, USA

[9]Brain Injury Research Center, TIRR Memorial Hermann, Houston, TX, USA

[10]Rehabilitation Institute of Michigan, Department of Psychology and Neuropsychology, Detroit, Michigan, USA

[11]Department of Physical Medicine and Rehabilitation, Wayne State University, Detroit, Michigan, USA

Abstract

Objective: To understand the factor structure of Health-Related Quality of Life (HRQOL) specific to caregivers of people living with Traumatic Brain Injury (TBI).

Design: Prospective, cross-sectional data collection.

Setting: Three TBI Model Systems rehabilitation hospitals, an academic medical center, and a military medical treatment facility.

Participants: 558 caregivers of people who have sustained a TBI (344 caregivers of civilians and 214 caregivers of service member/veterans; 85% female; 58% spouses; mean age = 46.12, SD =14.07 years) who have provided care for an average of 5.82 (SD = 5.40) years.

Interventions: Not Applicable.

Main Outcomes Measure: The Traumatic Brain Injury Caregiver Quality of Life (TBI-CareQOL) measurement system including 10 Patient-Reported Outcomes Measurement Information System (PROMIS) item banks (Anger, Anxiety, Depression, Social Isolation, Sleep Disturbance, Fatigue, Ability to Participate in Social Roles and Activities, Satisfaction with Social Roles and Activities, Emotional Support, Informational Support) and five TBI-CareQOL banks (Feelings of Loss–Self, Feelings of Loss–Person with TBI, Feeling Trapped, Caregiver-Specific Anxiety and Caregiver Strain).

Results: Confirmatory Factor Analysis (CFA) model fit indices were compared for 14 empirically and five theoretically derived models. CFA results indicated that the best model fit was for a six-factor model with dimensions that included: Mental Health, Social Support, Social Participation, Social Isolation, Physical Health, and Caregiver Emotion.

Conclusion: Results indicated a six-factor model provided the best model fit for HRQOL in caregivers of individuals with TBI. These results have utility for both research and clinical applications. Establishing the TBI-CareQOL's factor structure provides preliminary evidence of the measurement system's construct validity, helps inform the selection of measures for specific research or clinical interventions, and informs the development of composite scores.

Keywords

Each year approximately 2.87 million people[1] visit an emergency room; approximately 124,000 of these visits result in long-term disability.[2] In addition, approximately 310,000 Service Members and Veterans (SMVs) have sustained a TBI since 2000.; this includes 8,000 SMVs with moderate to severe TBI and 4,500 with penetrating TBI.[3] Although many people diagnosed with mild TBI will not experience long-term disability, others, especially

those with moderate to severe TBI, may experience long-term physical, emotional, cognitive, or social sequelae including posttraumatic stress disorder, depression or other mental health conditions.[4] Estimates suggest that approximately one-third of civilians[5] and SMVs with TBI[6] require home-based, readily accessible care one year after injury, and over a quarter of civilians with TBI are still receiving home-based care two to nine years post-injury.[7] Moreover, a significant number of caregivers of civilians[8] and SMVs[9–11] living with TBI report financial loss due to an inability to gain or maintain employment.

While healthcare systems have developed interventions and support services for civilians and SMVs living with TBI, this level and nature of support may not extend to family caregivers. Importantly, a caregiver's ability to adapt to new roles and responsibilities may have important implications for the person receiving care. For example, research indicates that people living with severe TBI who also reported poorer family functioning demonstrated less improvement in measures of disability, function, and employability.[12] Similarly, caregiver-perceived burden may also be linked to poorer outcomes for the person receiving care after a TBI.[13] Together, these results indicate that a more complete assessment of outcomes after TBI should include HRQOL assessment in both the person living with TBI and their family caregiver.

HRQOL is a multidimensional construct that includes elements of mental, physical, and social well-being.[14,15] Several modern measures of HRQOL have been developed, some of which assess HRQOL across populations and conditions while others are designed for specific populations or conditions. The Patient-Reported Outcomes Measurement System (PROMIS)[16] includes several measures of HRQOL that can be used across conditions and diagnoses, allowing for the development of tailored measurement batteries.[17] In addition to measures of HRQOL that are not specific to a patient's diagnoses, similar measurement systems have recently been developed to assess HRQOL for specific conditions. For example, the TBI-QOL was developed to assess HRQOL among people living with TBI[18] to provide content that is both generic (i.e., appropriate across clinical populations) and specific to individuals living with TBI. However, none of these measurement systems assess a family member's ability to adjust to the role of care provider.[12] Due to the complexity and heterogeneity of TBI, caregivers may experience unique challenges associated with caring for a family member living with a TBI. TBI-CareQOL measures build on the PROMIS framework, addressing challenges associated with caring for a person living with TBI to provide a more robust assessment of caregiver HRQOL.[19]

TBI-CareQOL[19] measures were designed to capture aspects of HRQOL identified by caregivers of people living with TBI. The conceptual model for this measurement system was developed through a series of nine focus groups composed of 55 caregivers of civilians living with TBI. The resulting model included four domains of caregiver HRQOL, namely social, mental, physical and cognitive health.[20] Importantly, social and mental health were identified as the most important elements of HRQOL by caregivers of people living with TBI.[21] These domains that emerged during the focus groups were used to identify conceptual overlaps with existing PROMIS measures. This process resulted in the identification of ten PROMIS measures (i.e. Anger,[22] Anxiety,[22] Depression,[22] Social Isolation,[23] Sleep Disturbance,[24] Fatigue,[25] Ability to Participate in Social Roles and

Activities,[23] Satisfaction with Social Roles and Activities,[23] Emotional Support,[26] and Informational Support[26]).

Five additional themes related to social and mental health were not addressed by existing PROMIS measures, including: feeling a sense of loss for the person living with TBI; feeling trapped by caregiving roles and responsibilities; feeling a loss of self likely due to the burden of caregiving roles and responsibilities; and anxiety regarding one's ability to provide care and strain due to the commitments of caregiving roles and responsibilities. Five sets of items, one for each of the themes that emerged during the focus groups that did not have a corresponding PROMIS measure, were developed using an iterative process that included input from subject matter experts with experience caring for a person living with TBI, and the inclusion of content from other HRQOL and patient-reported outcome measures. The process resulted in the development of five new PRO's that included social (i.e. Feelings of Loss-Person with TBI,[12] Feeling Trapped[19]) and mental health (i.e. Feelings of Loss-Self,[27] Caregiver-Specific Anxiety,[27] and Caregiver Strain, [28]) measures of caregiver HRQOL. The resulting measurement system, the TBI-CareQOL, is the first measure of HRQOL designed specifically to address the needs of caregivers of people living with TBI.

Individual measures that compose the TBI-CareQOL have demonstrated evidence supporting their validity (i.e., convergent, discriminant, and known-groups validity);[28] however, an evaluation of the latent factor structure of the TBI-CareQOL is needed to establish construct validity and to inform measurement selection (or the generation of composite scores) from the broader measurement system. This data could also be used to identify factors associated with caregiver HRQOL that may benefit most from targeted HRQOL-related interventions

Methods

Study Participants

Participants included 558 caregivers (214 caregivers of SMVs and 344 caregivers of civilians), who provided physical, financial, or emotional support to a person living with TBI. Caregivers of individuals with a wide range of TBI severity (as determined by the care recipient's treating clinician) were eligible to participate. Specifically, the caregivers of SMVs were eligible if their care recipient received a diagnosis of uncomplicated mild, complicated mild, equivocal, moderate, severe, or penetrating TBI made by the U.S. Department of Defense or the U.S. Department of Veteran Affairs. SMV caregivers were asked to estimate the amount of assistance they provided in completing activities of daily living with response options ranging from 0 "no assistance" to 10 "assistance with all activities". No SMV caregivers indicated "0" assistance. Caregivers of civilians living with TBI were eligible if their care recipient sustained a complicated mild, moderate, or severe TBI based on TBI Model Systems criteria.[29] Additional inclusion criteria for both SMV and civilian caregivers included: being at least 18 years of age or older, the ability to read and understand English, and experience providing care to a person living with TBI for a minimum of one-year post-injury. A detailed description of this sample is reported in Carlozzi et al.[30].

Measures

The TBI-CareQOL[19] includes 10 PROMIS[16] (i.e. Anger, Anxiety, Depression, Social Isolation, Sleep Disturbance, Fatigue, Ability to Participate in Social Roles and Activities, Satisfaction with Social Roles and Activities, Emotional Support, and Informational Support) and the five newly developed measures specific to caregivers of people living with TBI[31] (i.e. Feelings of Loss-Self, Feelings of Loss-Person with TBI, Feeling Trapped, Caregiver-Specific Anxiety, and Caregiver Strain). All measures (i.e. the 10 PROMIS and the five newly developed TBI-CareQOL measures) were scored on a T-score metric (M=50 and SD=10) with higher scores indicating greater levels of the construct being assessed (i.e., for "negative" constructs such as Anger and Depression, higher scores indicate greater symptoms, while for "positive" constructs such as Emotional Support and Ability to Participate in Social Roles and Activities, higher scores indicate greater function). All PROMIS measures were administered as computerized adaptive tests; for the five new TBI-CareQOL measures, simulated computer adaptive test scores were estimated from full bank data using the Firestar software package.[32] Evidence of the reliability and preliminary validity of the 15 TBI-CareQOL measures have been demonstrated in prior research.[19,33]

Procedures

Approval was granted by each site's institutional review board prior to the initiation of study activities. Caregivers provided informed consent (specifically, one site granted a waiver of consent, another site allowed phone consent and third site required written consent). Each of the 10 PROMIS and the five newly developed TBI-CareQOL measures were administered using the Assessment Center testing platform (https://www.assessmentcenter.net). Assessments were completed using either a personal or publicly available computer equipped with an internet connection.

Analysis Plan

Alternative factor structures were developed based on expert input and examination of the factor structures of other PRO measurement systems. Specifically, we applied conceptual frameworks that were used to develop the TBI-QOL, a measure of HRQOL for people living with TBI that consists of seven factors (Participation, Physical Symptoms, Physical Function, Cognitive Function, Positive Emotion, Sense of Self and Negative Emotion) and the Neuro-QOL, a measure of HRQOL for people living with neurological disorders that consists of four factors (Physical, Cognitive, Emotional and Social). This process resulted in 14 hypothetical factor structures (i.e., models 1-9, 13, and 16-19). A panel of subject matter experts with expertise in TBI, measurement development, and care management reviewed these 14 models and recommended the inclusion of five additional models that included alternative conceptualizations of Negative Affect (i.e., models 10 and 11), Social Participation and Support (i.e. models 11, 12 and 14), and Emotional Health (i.e. models 14 and 15). In total, this process yielded 19 models (Table 1).

Pearson correlation coefficients for the 10 PROMIS and five newly developed TBI caregiver-specific measures were calculated to assess conceptual overlap between measures (Table 2). Confirmatory factor analyses were conducted using IBM SPSS and AMOS (Version 24) to test model fit for each of the 19 factor models. Model fit was assessed using

the following five indices: Root Mean Square Error of Approximation (RMSEA) of less than 0.08; Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI) of .95 or greater; Chi-square divided by Degrees of Freedom less than or equal to 3, and the smallest absolute value of the Akaike Information Criterion (AIC).[34–36] Each of these five indices provides a different means to assess fit. Briefly, RMSEA is an absolute measure of model fit that assumes a hypothetical model with perfect parameter estimates compared to the population covariance matrix. Acceptable values of RMSEA range from 0.01 (excellent model fit) to 0.08 (mediocre model fit).[37] CFI assesses the difference between the data and the hypothesized model while adjusting for sample size, and the TLI represents the difference between a chi-square value for a hypothesized model and a chi-square of the null model. For both CFI and TLI, values 0.90 indicate "good" model fit, and values 0.95 indicates excellent model fit. Kenny notes that CFI is more commonly reported in the literature, however, CFI values may increase as models become more complex.[38] We have reported both CFI and TLI model fit indices. CMIN/DF (i.e. χ^2/df) attempts to adjust the traditional chi-square test that may produce liberal estimates of model fit. CMIN/DF is a traditional measure of model fit that was reported for the sake of completeness.[38] It should be noted that no agreed standard has been established for CMIN/DF, however, non-significant values suggest "acceptable" model fit.[36,38,39] A cut-off CMIN/DF value of 3.0 was used in the current study based on published recommendations.[36] AIC, a measure of comparative fit, was used to assess fit between competing models. Lower AIC values are interpreted as better fitting models.[36] To assess differences between models, AIC values for the baseline model (i.e. a single-factor model) were subtracted from AIC values for each of the 18 alternative models.[40] Model fit indices, including differences in AIC values (i.e. baseline – alternative model) were used to retain factor models for further consideration.

Results

Detailed descriptive statistics for the study sample have been reported by Carlozzi et al.[19] A summary of this information is provided in Table 3. Item characteristics for each measure included in the TBI-CareQOL are reported in Table 4. Correlations between measures ranged from −0.68 (social isolation and ability to participate in social roles and activities) to 0.82 (informational support and emotional support; Table 2).

Findings suggested that the six-factor model that included Negative Affect (Anger, Anxiety and Depression), Social Health (Informational and Emotional support), Social Participation (Ability to Participate in Social Roles and Activities and Satisfaction with Social Roles and Activities), Social Isolation (Social Isolation and Feeling Trapped), Physical Health (Sleep Disturbance and Fatigue) and Caregiver-Specific Emotional Health (Feelings of Loss-Self, Feelings of Loss-Person with TBI, Caregiver-Specific Anxiety and Caregiver Strain) was the best fitting model (Table 5; Supplemental Table S1).

The investigative team, with the assistance of a statistical consultant, discussed the theoretical rationale for the factor structures of the three models that met published recommendations for minimum standards of fit (i.e. models 3, 10 and n).[36–38–39] It was agreed that Model 3 (a two-factor model) lacked conceptual clarity and as such, models 10 (a six-factor model) and 11 (a five-factor model) were retained for further analysis. The

difference between models 10 and 11 lay in the conceptualization of Social Health. In Model 10, Social Health is conceptualized in terms of Informational and Emotional Support which represents a single latent factor. In contrast, Model 11 combines Social Participation and Support (Ability to Participate in Social Roles and Activities and Satisfaction with Social Roles and Activities) with Informational and Emotional Support as a single factor. In reviewing these models, it was agreed that social and emotional aspects of caregiving (i.e. Informational and Emotional Support) may differ from more instrumental forms of support (i.e. Ability to Participate in Social Roles and Activities and Satisfaction with Social Roles and Activities). Differences in fit between models 10 and 11 were similar (i.e. RMSEA, CFI, TLI and CMIN/DF). However, AIC, a measure of comparative model fit, indicates that Model 10 (AIC = 361.29) had the smallest AIC value when compared to models 1 (663.70), 3 (470.03) and 11 (366.61) and the largest difference with the baseline one-factor model (Model 10 AIC - Model 1 AIC = −302.41), compared to differences observed between the other two models retained for analyses (i.e. Model 3 AIC - Model 1 AIC = −193.67 and Model 11 AIC - Model 1 AIC = −297.09). Given the small differences in fit between models 1 and 3, we asked members of the investigative team to individually evaluate the theoretical and practical utility of both models. The team reached consensus that Model 10 represented a more nuanced model of HRQOL for people providing care to a person living with TBI.

Discussion

The 6-factor structure of the TBI-CareQOL measurement system (Negative Affect, Social Health, Social Participation, Social Isolation, Physical Health and Caregiver-Specific Emotional Health) provides preliminary evidence of the measurement system's construct validity. Construct validity is evident in the similarities of these findings with a model of HRQOL that is specific to people living with TBI,[41] as well as the similarities with the general framework for the Neuro-QoL measurement system (that is specific to persons with neurological conditions).[42] All three measurement systems (TBI-CareQOL, TBI-QOL and Neuro-QoL) include mental, physical and social health. In addition, both the TBI-CareQOL (i.e. caregiver HRQOL) and TBIQOL (i.e. HRQOL among people living with TBI), mental health includes both positive and negative affect, as well as positive and negative aspects of social support. This would indicate that it is important to examine both the positive and negative aspects of both mental and social health for both caregivers and persons living with TBI. Results of this confirmatory factor analysis provide an initial set of targets for caregiver HRQOL related interventions.[43]

In addition, the six-factor model that emerged in our analyses suggests that the valence of a factor (i.e. factors that result in positive or negative evaluations) may account for unique variance in measures of HRQOL. Specifically, the factor structure of caregiver HRQOL suggests that caregiver social participation may be more accurately represented by two factors; one that assesses positive aspects of social participation and another that assesses social isolation. These two measures of social participation may not simply represent two ends of a single continuum, but rather two distinct aspects of HRQOL.[44] We also suspect that we would have observed a similar pattern of results for mental health outcomes had we included measures of positive mental health in our model. Research is currently underway to

assess how positive mental health may fit into the six-factor model that emerged in the current analysis.

Findings for a 6-factor model of HRQOL are also relevant to clinical interventions focused on caregivers, as well as outcomes measurement selection for clinical research in caregivers. The findings reveal that caregivers' HRQOL is multidimensional, and that caregiver interventions may need to target multiple domains to effect positive changes in overall HRQOL. Broad treatment modalities have been shown to be effective for reducing emotional distress, such as psychotherapies and/or psychotropic medications, may improve HRQOL in certain domains, such as mental health.[45,46] However, decreases in HRQOL that are specific to the caregiving role may require more specific intervention, such as training caregivers how to manage TBI-related deficits (i.e., cognitive impairments ; irritability) and provision of caregiver-specific resources, such as support groups and respite care.[47,48] Specific CareQOL item banks may be selected to assess progress for specific treatments, allowing for a comprehensive, yet individualized approach to treatment evaluation.

Furthermore, data from this study can be used to pick and choose multiple measures in the target area of intervention, as well as a single measure from each of the other factors to determine if the intervention has an impact on these additional domains; in this manner, researchers can balance participant burden with comprehensive assessment of HRQOL for these caregivers. Furthermore, these results can also inform the development of composite scores that represent these different factors. Composite scores are more psychometrically robust and tend to be easier to interpret and more clinically useful than any single PRO assessment score. As such, composite scores that represent the size factors identified here may provide a more clinically useful endpoint than any single measure in isolation. Composite scoring could also allow researchers to evaluate the effectiveness of caregiver and family interventions on both general and specific aspects of caregiver HRQOL.

Study Limitations

While these results provide additional evidence supporting the construct validity and clinical utility of the TBI-CareQOL's factor structure, it is important to acknowledge several study limitations. Participants in this study had, on average, more than five years of experience providing care to a person living with TBI. Moreover, participating caregivers were primarily Caucasian and spouses of the person for whom they provided care, these demographic characteristics may not generalize to new caregivers (i.e. during the acute phases of recovery), ethnic minorities, or non-spousal caregivers. It is also important to note that our sample consisted primarily of female caregivers ($n = 477$; 85%), while most care recipients were male (n = 470; 84%). Research indicates that the experience of caregiving may be moderated by a caregiver's sex due to cultural expectations that influence the types of care provided and the support these caregivers receive.[49–51] Traditional models of HRQOL allow for generalized comparisons within and between populations, but they may not be sensitive to subtle, yet important, differences for persons with (or caring for) specific clinical conditions. Our results indicate that social participation may contribute to both positive and negative outcomes for caregivers. Importantly, prior conceptualizations of caregiver HRQOL may have inadvertently focused on negative consequences associated

with being a caregiver, without assessing positive outcomes that could be leveraged to mitigate some of the challenges caregivers may face. Future studies should assess how social participation and isolation among caregivers may uniquely affect outcomes among people living with TBI. Additional researches with larger and more diverse samples are needed to replicate the six-factor model that emerged in this analysis. Importantly, the version of the TBI-CareQOL used in the current study did not include measures of positive affect, a construct that has demonstrated beneficial outcomes for caregivers.[52,53]

Conclusions

Patient-reported outcome measures are an important tool for measuring HRQOL across conditions and populations. However, specific conditions may embody unique factors that contribute to HRQOL. Results of the current study suggest that HRQOL among caregivers of people living with TBI include both generic and caregiver-specific aspects. These different factors, Negative Affect, Social Health, Social Participation, Social Isolation, Physical Health and Caregiver-Specific Emotional Health, are prime targets for clinical interventions designed to improve caregiver HRQOL. In addition, studies that are focusing on a single factor might also consider including at least a single measure from each of the other five factors to ensure that they are capturing information across each of these different important aspects of these caregivers' HRQOL. In addition, these findings can be used to inform the creation of composite scores of these different domains of HRQOL that are likely to provide clinically useful information.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

List of Abbreviations:

AIC	Akaike Information Criterion
CAT	Computer Adaptive Test
CFA	Confirmatory Factor Analyses
CMIN/DF	Chi-square divided by Degrees of Freedom
CFI	Comparative Fit Index
HRQOL	Health-Related Quality of Life

PROMIS	Patient Reported Outcomes Measurement Information System
RMSEA	Root Mean Square Error of Approximation
SMV	Service Members and Veterans
TBI	Traumatic Brain Injury
TBI-CareQOL	Traumatic Brain Injury Caregiver Quality of Life (measurement system)
TBI-QOL	Traumatic Brain Injury – Quality of Life (measurement system)
TLI	Tucker-Lewis Index

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Table 1:

Factor Models and Measurement Domains

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
1	One-Factor HRQOL (Baseline Model)	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
2	HRQOL,	●	●	●	●	●	●	●	●			●	●	●	●	●
	Social									●	●					
3	HRQOL, Social	●	●	●	●	●	●	●	●	●	●					
	Emotional Health (Feeling Loss, Trapped, Caregiver Anxiety and Strain)											●	●	●	●	●
4	Generic HRQOL	●	●	●	●	●	●	●	●							
	Emotional Health (Feeling Loss, Trapped, Caregiver Anxiety and Strain)											●	●	●	●	●
	Social Health									●	●					
5	Emotional Health (Negative Affect, Feeling Loss, Trapped and Strain)	●	●	●								●	●	●	●	●
	Social Participation and Support				●			●	●	●	●					
	Physical Health					●	●									

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
6	Emotional Health (Negative Affect, Feeling Loss, Trapped and Strain)	●	●	●								●	●	●	●	●
	Social Participation (with isolation)				●			●	●							
	Physical Health					●	●									
	Social Health									●	●					
7	Emotional Health (Negative Affect, Feeling Loss and Strain)	●	●	●								●	●		●	●
	Social Participation and Support (with isolation)				●			●	●	●	●			●		
	Physical Health					●	●									
8	Emotional Health (Negative Affect, Feeling Loss, Feeling Loss and Strain)	●	●	●								●	●		●	●
	Social Health									●	●					
	Social Participation (Feeling Trapped and Isolation)				●			●	●					●		
	Physical Health					●	●									

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
9	Emotional Health (Negative Affect, Feeling Loss and Strain)	●	●	●								●	●		●	●
	Social Health									●	●					
	Social Participation							●	●							
	Social Isolation				●									●		
	Physical Health					●	●									
10	Negative Affect	●	●	●												
	Social Health									●	●					
	Social Participation							●	●							
	Social Isolation				●									●		
	Physical Health					●	●									
	Caregiver-Specific Emotional Health							●	●	●	●	●	●		●	●
11	Negative Affect	●	●	●												
	Social Participation and Support															
	Social Isolation				●											
	Physical Health					●	●									

Arch Phys Med Rehabil. Author manuscript; available in PMC 2021 July 01.

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
12	Caregiver-Specific Emotional Health											●	●		●	●
	Emotional Health (Negative Affect, Feeling Loss and Strain and Support)	●	●	●								●	●		●	●
	Social Participation and Support							●	●	●	●					
	Social Isolation				●									●		
	Physical Health					●	●									
13	Emotional Health (Negative Affect Feeling Loss and Strain)	●	●	●								●	●		●	●
	Social Participation							●	●							
	Social Isolation				●									●		
	Physical Health					●	●									
	Social Health									●	●					
14	Emotional Health (Negative Affect and Caregiver Strain)	●	●	●											●	●
	Social Participation and Support							●	●	●	●					

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
	Social Isolation				●									●		
	Physical Health					●	●									
	Feelings of Loss (Self and Other)											●	●			
15	Emotional Health (Negative Affect and Caregiver Strain)	●	●	●											●	●
	Social Participation							●	●							
	Social Isolation				●									●		
	Physical Health					●	●									
	Feelings of Loss (Self and Other)											●	●			
	Social Health									●	●					
16	Emotional Health (Negative Affect, Health, Feeling Trapped and Caregiver-Specific Emotion)	●	●	●	●	●	●					●	●	●	●	●
	Social Participation and Support							●	●	●	●					
17	Emotional Health (Negative Affect, Health,	●	●	●	●	●	●					●	●	●	●	●

Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
	Feeling Trapped and Caregiver-Specific Emotion)															
	Social Participation							●	●							
	Social Health									●	●					
18	Anxiety (General and Caregiver Specific)		●												●	
	Social Participation and Support							●	●	●	●					
	Social Isolation				●									●		
	Physical Health					●	●									
	Emotional Health (Anger, Depression Feelings of Loss Self / Other and Strain)	●		●								●	●			●
19	Anxiety (General and Caregiver Specific)		●												●	
	Social Participation							●	●							
	Social Isolation				●									●		
	Physical Health					●	●									
	Emotional Health (Anger, Depression	●		●								●	●			●

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Model Number	Hypothesized Factors	Anger	Anxiety	Depression	Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain
	Feelings of Loss Self / Other and Strain															
	Social Health									●	●					

● indicates which measurement domains were included in each hypothesized factor

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Table 2:

Correlations between TBI-CareQOL Measures

Measure	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Anger^	1														
2. Anxiety^	0.79**	1													
3. Depression^	0.78**	0.83**	1												
4. Social Isolation^	0.59**	0.63**	0.65**	1											
5. Sleep Disturbance^	0.51**	0.55**	0.51**	0.45**	1										
6. Fatigue^	0.63**	0.69**	0.66**	0.59**	0.66**	1									
7. Ability to Participate in SRA^	−0.56**	−0.64**	−0.60**	−0.68**	−0.50**	−0.66**	1								
8. Satisfaction with SRA^	−0.51**	−0.56**	−0.53**	−0.60**	−0.48**	−0.57**	0.72**	1							
9. Emotional Support^	−0.30**	−0.35**	−0.37**	−0.51**	−0.28**	−0.31**	0.42**	0.47**	1						
10. Informational Support^	−0.33**	−0.35**	−0.39**	−0.47**	−0.26**	−0.29**	0.40**	0.47**	0.82**	1					
11. Feelings of Loss-Self~	0.59**	0.62**	0.64**	0.64**	0.41**	0.53**	−0.66**	−0.55**	−0.38**	−0.40**	1				
12. Feelings of Loss-Person with TBI~	0.44**	0.46**	0.48**	0.44**	0.29**	0.37**	−0.47**	−0.35**	−0.21**	−0.24**	0.74**	1			
13. Feeling Trapped~	0.46**	0.51**	0.50**	0.59**	0.42**	0.50**	−0.67**	−0.56**	−0.36**	−0.35**	0.73**	0.52**	1		
14. Caregiver-Specific Anxiety~	0.61**	0.62**	0.62**	0.56**	0.41**	0.50**	−0.57**	−0.45**	−0.33**	−0.32**	0.76**	0.59**	0.66**	1	
15. Caregiver Strain~	0.62**	0.66**	0.65**	0.61**	0.48**	0.63**	−0.66**	−0.55**	−0.40**	−0.40**	0.79**	0.58**	0.68**	0.70**	1

SRA = Social Roles and Activities

^ PROMIS Measures

~ TBI-CareQOL Measures

** *p* .001

Table 3:

Demographic Characteristics of Caregivers and Care-Recipients

Categorical Descriptors	n^*	%
Caregiver Sex		
Male	81	15%
Female	477	85%
Care Recipient Sex		
Male	470	84%
Female	88	16%
Marital Status (Married)	400	72%
Relationship to Care Provider		
Spouse / Partner	325	58%
Child	29	5%
Parent	128	23%
Other	76	14%
Level of Injury [^]		
Uncomplicated Mild	41	7%
Complicated Mild	65	12%
Equivocal	33	6%
Moderate	77	14%
Severe	197	35%
Missing or Unknown [^]	145	26%
Race		
White	418	75%
Black	77	14%
American Indian / Alaskan Native	6	1%
American Indian / Alaskan Native white	5	1%
Asian	10	2%
Other	33	6%
More than One Race	9	2%
Ethnicity		
Hispanic / Latino Origin or Descendant	59	11%
Continuous Descriptors	**Mean**	**SD**
Caregiver Age	46.12	14.07
Care Recipient Age	40.32	12.63
Years Since Injury	7.60	5.09
Years of Care Provided (self-report)	5.82	5.40

Note: Sample percentages for race were rounded to the nearest how number; ethnicity was asked in addition to race (i.e. "are you of Hispanic or Latino origin or descent?")

*
n = 558 were included in the confirmatory factor analysis

^
Level of injury data not available for Veterans seen at civilian data collection site

Table 4:

Descriptive Statistics for Study Measures and Tests of Normality

Measure*		Min	Max	Mean (SD)	Skew	Kurtosis
A.	PROMIS Anger	28.9	85.2	53.37 (9.93)	−0.12	0.11
B.	PROMIS Anxiety	32.9	84.9	54.84 (9.54)	−0.07	0.04
C.	PROMIS Depression	34.2	84.4	52.09 (9.79)	0.14	0.01
D.	PROMIS Social Isolation	31.8	80.1	50.44 (9.94)	−0.07	−0.21
E.	PROMIS Sleep Disturbance	26.3	83.8	54.00 (10.02)	−0.03	0.38
F.	PROMIS Fatigue	24.3	84.7	54.35 (9.99)	−0.12	0.29
G.	PROMIS Ability to Participate in Social Roles and Activities (SRA)	21.5	67.5	49.16 (9.69)	0.18	−0.25
H.	PROMIS Satisfaction with Social Roles and Activities (SRA)	22.0	68.7	46.00 (8.84)	0.54	0.84
I.	PROMIS Emotional Support	20.2	66.2	48.13 (9.27)	0.20	−0.13
J.	PROMIS Informational Support	23.2	69.8	48.98 (10.40)	0.16	−0.34
K.	TBI-CareQOL Feelings of Loss-Self	30.3	76.0	50.06 (9.51)	−0.08	−0.39
L.	TBI-CareQOL Feelings of Loss-Person with TBI	26.1	74.6	49.91 (9.52)	−0.12	−0.02
M.	TBI-CareQOL Feeling Trapped	34.2	73.3	50.05 (9.60)	−0.15	−0.82
N.	TBI-CareQOL Caregiver-Specific Anxiety	27.9	80.6	50.11 (9.66)	−0.15	0.02
O.	TBI-CareQOL Caregiver Strain	27.0	77.7	50.06 (9.72)	−0.22	−0.14

*
Letters for measures correspond to dimensions included in factors in Table 5

Table 5:

Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss-Self	Feelings of Loss-Person with TBI	Feeling Trapped	Caregiver-Specific Anxiety	Caregiver Strain	RMSEA (≤ .08)	CFI (≥ .95)	TLI (≥ .95)	CMIN/DF (≤ 3)	Absolute AIC (< better)	Baseline (Mode 1) - Model AIC (≥ 3 clinically meaningful)
●	●	●	●	●	●	●	●	●	●	●	●	0.13	0.91	0.88	9.90	663.70	0
●	●	●	●	●	●	●						0.08	0.95	0.94	4.84	470.03	−193.67
							●	●	●	●	●						
●	●		●	●	●	●											
	●	●							●								
							●	●		●	●	**0.07**	**0.97**	**0.96**	**3.64**	**361.29**	**−302.41**
●			●	●	●	●						0.07	0.97	0.96	3.62	366.61	−297.09
●									●								

Social Isolation	Sleep Disturbance	Fatigue	Ability to Participate SRA	Satisfaction with SRA	Emotional Support	Informational Support	Feelings of Loss- Self	Feelings of Loss- Person with TBI	Feeling Trapped	Caregiver- Specific Anxiety	Caregiver Strain	RMSEA (≤.08)	CFI (≥.95)	TLI (≥.95)	CMIN/ DF (≤3)	Absolute AIC (< better)	Baseline (Mode 1) - Model AIC (≥3 clinically meaningful)
	•	•					•	•		•	•						

othesized factor