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The development of a two new computer adaptive tests to evaluate feelings of loss in caregivers of individuals with traumatic brain injury: TBI-CareQOL Feelings of Loss-Self and Feelings of Loss-Person with Traumatic Brain Injury

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Abstract

Objective: To develop new patient-reported outcome (PRO) measures to better understand feelings of loss in caregivers of individuals with traumatic brain injury (TBI).

Design: Cross-sectional survey study.

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

Participants: Five-hundred-sixty caregivers of civilians with TBI (n=344) or service members/veterans (SMVs) with TBI (n=216).

Interventions: Not applicable.

Main Outcome Measures: TBI-CareQOL Feelings of Loss-Self and TBI-CareQOL Feelings of Loss-Person with Traumatic Brain Injury Item banks

Results: While the initial exploratory and confirmatory factor analyses of the Feelings of Loss item pool (98 items) potentially supported a unidimensional set of items, further analysis indicated two different factors: Feelings of Loss-Self (43 items) and Feelings of Loss-Person with TBI (20 items). For Feelings of Loss-Self, an additional 13 items were deleted due to item-response theory based item misfit; the remaining 30 items had good overall model fit (Confirmatory Fit Index [CFI]=0.96, Tucker Lewis Index [TLI]=.96, Root Mean Squared Error [RMSEA]=.10). For Feelings of Loss-Other, 1 additional item was deleted due to an associated high correlated error modification index value; the final 19 items evidenced good overall model fit (CFI=0.97, TLI=.97, RMSEA=.095). The final item banks were developed to be administered as either a CAT or a short-form. Clinical experts approved the content of the 6-item short forms of the two measures (three-week test-retest was r=.87 for Feelings of Loss-self and r=.85 for Feelings of Loss-Person with TBI)

Conclusions: The findings from this study resulted in the development of two new PROs to assess feelings of loss in caregivers of individuals with TBI; TBI-CareQOL Feelings of Loss-Self and TBI-CareQOL Feelings of Loss-Person with TBI. Good psychometric properties were established and a short-form was developed for ease of use in clinical situations. Additional research is needed to determine concurrent and predictive validity of these measures in the psychological treatment of those caring for persons with TBI.

Keywords

Health-related quality of life; PROMIS; TBI-CareQOL; traumatic brain injury; caregiver; caregiver strain; caregiver burden; patient reported outcome

Sustaining a moderate to severe traumatic brain injury (TBI) can lead to challenges in everyday functioning.[1,2] Functional impairments and disability can result in the need for

assistance in everyday activities.[3,4] Family members are often required to assume the role of informal "caregiver" and bear primary responsibility for assistance with physical, cognitive, financial, and leisure activities.[5–9] This caregiver role can be associated with negative outcomes, including changes in caregiver health-related quality of life (HRQOL).[10–17] Feelings of loss for both caregivers and the person with TBI can also negatively impact caregiver HRQOL.[18]

Prior qualitative work has described caregivers' feelings of loss following TBI.[18,19] Specifically, caregivers experience feelings related to loss of their loved one's future potential. Caregivers also experience feelings related to loss of their own relationships and future plans.[18,20] This concept of feelings of loss is consistent with findings of objective changes in social roles for caregivers after TBI, including changes in employment, social activities, and relationships.[21] Such changes and feelings are congruent with the stress-process model of caregiving[22] which is characterized by multifaceted interactions between caregiving demands and personal resources c factors (e.g., age, gender) interact with primary and secondary stressors associated with caregiver demands (i.e., problematic conditions, experiences, and activities). Primary stressors result directly from the injury and include the cognitive, behavioral and functional status of the care-recipient. Secondary stressors (including feelings of loss) arise in response to primary stressors and include interpersonal strain between the caregiver and other family members including the care-recipient, economic and social strain, self-esteem, perceptions of caregiver mastery, and competence. Both primary and secondary stressors can be mediated by variables such as social support and coping style/ability. The complex interactions among these three domains result in either positive or negative behavioral outcomes for the caregiver, including poor HRQOL and/or health problems.

Feelings of loss can also be considered within the caregiver model of grief.[23] This model conceptualizes caregiver anticipatory grief, or the behavioral reactions to personally significant losses that are experienced when caring for a living individual, as a normal phase of bereavement like that associated with an actual death. Similarly, the theory of ambiguous loss[24,25] can be defined as a situation in which the care-recipient is physically present (i.e., living), but psychologically absent. In a caregiving context, such feelings can psychologically immobilize both the caregiver and care-recipient, and result in negative outcomes for both.

Much of our knowledge regarding feelings of loss in caregivers is derived from research with dementia caregivers, in whom feelings of grief and loss are common. These feelings include ambiguity towards the care-recipient and perceptions of loss due to the change in the caregiver-care-recipient relationship (e.g., loss of emotional and physical intimacy).[26–32] Caregivers of individuals with dementia also express feelings of loss related to their occupation,[33] physical well-being (e.g., sleep, general health problems),[31.33] social well-being,[26,28,31,33] future hopes/dreams plans,[29–32] as well as loss related to their personal identity.[34] Additionally, they experience feelings of loss for the personality changes,[27–29,31,32,35] pre-injury abilities,[26] and future life[31,32] of the person with dementia.

In order to better understand feelings of loss in caregivers of individuals with TBI, we developed new patient-reported outcome (PRO) measures that are specific to caregivers of civilians and service member/veterans with TBI. These new measures were developed according to established guidelines,[36] as a part of the TBI-CareQOL measurement system[37] which includes both generic patient reported outcomes (PROs) from the existing Patient Reported Outcomes Measurement Information System (PROMIS),[38,39] as well as new, TBI-caregiver-specific PROs. In this report, we describe the development of two new measures of feelings of loss for use in caregivers of individuals with TBI.

Methods

Study Participants

Five hundred and sixty caregivers of individuals with TBI were enrolled in this study; 145 also completed a 3-week retest. Details of the sample are provided elsewhere.[37]

Caregivers of civilians with TBI must have been caring for an individual with a medically documented complicated mild, moderate, or severe TBI, based on TBI Model Systems criteria.[40] Caregivers of SMVs with TBI must have been caring for a person with a TBI that was medically documented by a healthcare facility. For both subsamples, the caregiver must have been able to read/understand English, and the person with TBI had to be ≥16 years of age at the time of injury and at least one-year post-injury. Caregiver status was defined as providing physical assistance, financial assistance, or emotional support to an individual with a TBI. The study was conducted in accordance with the local institutional review boards and caregivers provided consent before participating in this study.

Measures

TBI-CareQOL Feelings of Loss Item Pool: The initial Feelings of Loss item pool (which included 75 items) was based on focus group discussion among caregivers of civilians and SMVs with TBI[19,41] and included items that examined feelings of loss with regard to the individual with TBI (including loss of abilities, loss of potential/future, and changes in behavior/personality), as well as losses related to the caregivers themselves (including loss of self, relationships, activities and future plans). Items were added and/or deleted according to an iterative process (details in Carlozzi et al.[37]). The final item pool was comprised of 98 items.

Statistical Analyses

Sample size considerations are reported elsewhere.[37] Classical test theory (CTT) and item response theory (IRT) were used to develop new measures. Whereas CTT requires successful completion of all test items in order to estimate an individual's "true score,"[42] IRT can be used to generate a score based on any subset of items (which allows for the retention of only the best performing items). IRT-based calibrations can also be used to program CAT administration for a PRO measure.

Establishing a Unidimensional Set of Items.—An iterative process using full-sample exploratory and confirmatory factor analysis (EFA, CFA) and clinical input[43–45] was used to

select a unidimensional set of items (conducted using Mplus version 7.4[46]). Using EFA, we focused on the following criteria to support unidimensionality: the ratio of eigenvalue 1 to eigenvalue 2 > 4 and the proportion of variance accounted for by eigenvalue 1>.40. Items with sparse cells (response categories with n<10 respondents), low correlations for item-adjusted total scores (<0.40), or non-monotonicity (according to item-rest plots and expected score by latent trait plots obtained from a non-parametric IRT model [Testgraf Software[47]]) were excluded. Initial CFAs flagged items with low factor loadings (lx <0.50) and items demonstrating local dependence (residual correlation >0.20; correlated error modification index ≥100).[43–45] Once a unidimensional set of items was established, IRT was used to further model the data, with Samejima's graded response model (GRM)[48] employed to establish item parameters (analyses conducted in IRTPRO version 3.1[49]). Items displaying significant misfit (S-X2, p<0.01) were excluded based on these GRM-related analyses.

Differential item functioning (DIF; conducted using the R package LORDIF (Version 0.3–2)[50,51] provides an indication of unexpected behavior by an item on a test; it is when an item performs differently for a subgroup of participants when it should not (e.g., men perform better than women). The most important indicator of DIF is not whether items systematically differentiate relevant subgroups, but whether they do so in an unpredicted way. DIF was used to identify unexpected item bias for age (≤40 vs. >40 years), education (<college vs. ≥college), and caregiver status (civilians vs. SMVs). Items showing impactful DIF were excluded (Nagelkerke pseudo-R2 change ≥0.20, plus >2% of DIF-corrected vs. uncorrected score differences exceeding uncorrected score standard errors). These analyses used a hybrid IRT ability score-ordinal logistic regression framework.[52]

As a final check of unidimensionality, final CFA modeling was conducted. Standard fit criteria were used: comparative fit index (CFI) ≥0.95, Tucker-Lewis index (TLI) ≥0.95, and root mean square error of approximation (RMSEA) <0.15.[53–56]

Item Bank Scores.—Final item banks permit administration of computer adaptive tests (CATs) or fixed-length short-forms (SF). Firestar simulation software was used to simulate CAT scores.[57] A 6-item short form was selected using clinical expert opinion on item content and range of concept coverage and item calibration-related statistics (e.g., item slope, thresholds, average item difficulty, item information).

Results

Study Participants

A total of 560 caregivers of individuals with TBI participated in this study (n=344 caregivers of civilians with TBI and n=216 caregivers of SMVs with TBI). Briefly, caregivers were on average 46.1 years of age (SD=14.1) and were primarily female (86%). Caregivers were also primarily Caucasian (77.2%), followed by African American (13.8%), and other races (8.8%; 0.2% of the sample omitted this question); 10.6% indicated they were of Hispanic or Latino descent. With regard to education, 39.5% had a college degree, followed by some college (42%), or a high school degree or less (18.6%). Most were married or cohabitating (74.2%), followed by never married (11.3%), separated or divorced (9.9%) and widowed (3.9%; marital status was missing for 0.7% of the sample). Most participants were in the

caregiver role for an average of 5.8 years (SD=5.4), and most were spouses (58.2%), followed by parents (22.9%), children or other family relations (12.9%), and "other" relationships (e.g., friends; 5.9%). Most (84.2%) of participants were caring for a male with TBI, and the average age of the person with TBI was 40.3 years of age (SD=12.6).

Establishing a Unidimensional Set of Items.—Initial evidence from EFA from the initial item pool (98 items) indicated that the full item set was potentially unidimensional. One item was eliminated due to having a low item-adjusted total score correlation, 18 items were deleted due to high residual correlations, and nine items were deleted due to high correlated error modification index values. Subsequent CFA and IRT modeling of the remaining 70 items indicated poor overall and individual item fit. Thus, a new EFA was conducted on the remaining 70 items which revealed a 4-factor solution (Table 1). This solution included two distinct aspects of Feelings of Loss: caregivers' feelings of loss about their own lives (Feelings of Loss-Self, 43 items), and caregivers' feelings of loss about the lives of those for whom they are providing care (Feelings of Loss-Person with TBI, 20 items). The third and fourth factors did not include enough items for consideration as stand-alone measures.

For Feelings of Loss-Self (43 items), follow-up CFA did not identify any items with low factor loadings, high residual correlations, or high correlated error modification index values. No items displayed non-monotonicity, and no items exhibited DIF. However, 13 items were deleted due to IRT-based item misfit statistics. The final Feelings of Loss-Self bank was comprised of 30 items (Table 2).

For Feelings of Loss-Person with TBI (20 items), follow-up CFA also did not identify any items with low factor loadings or high residual correlations; however, one item was excluded due to an associated high correlated error modification index value. None of the items displayed non-monotonicity, nor did they exhibit DIF. No items had statistically significant IRT-based item misfit. The final Feelings of Loss-Person with TBI bank was comprised of 19 items (Table 2).

Final Item Bank Criteria.—The final CFA model suggested good overall model fit for both Feelings of Loss-Self and Feelings of Loss-Person with TBI (see Table 3).

Final item banks parameter estimates are shown in Table 4. Score-level reliability for Feeling of Loss-Self was excellent from theta= −1.2 to +2.8, with expected score-level reliability ≥90; score-level reliability from the expanded theta range from −1.6 to +2.8 was very good to excellent (at least ≥.80), while score-level reliability at further expanded theta range from −2.0 to +2.8 was good to excellent (at least ≥.70). For Feelings of Loss-Person with TBI, score-level reliability was excellent from theta= −1.6 to +2.0, with expected score-level reliability ≥.90; score-level reliability at the expanded theta range from −2.0 to +2.4 was very good to excellent (at least ≥.80), while score-level reliability at the further expanded theta range from −2.4 to +2.4 was good to excellent (at least ≥.70). Figures 1 and 2 show test information plots for Feelings of Loss-Self and Feelings of Loss-Person with TBI, respectively.

CAT Simulation.—For Feelings of Loss-Self, the correlation between item bank and CAT scores was 0.97 (Figure 3). The standard deviation of the differences between full item bank and CAT scores was 0.23, and the root-mean-square deviation (RMSD) of the two score sets was 0.23. The most common CAT length was 4 items (n=298, 53.2%), the second most common length was 5 items (n=80, 14.3%), and the third most common length was 12 items (n=79, 14.1%), with 12-item CATs being the longest CATs administered. The mean number of items administered for the Feelings of Loss-Self CAT was 5.9. For 4-item CATs, observed thetas ranged from −0.42 to +1.88; the theta range for 5-item CATs was similar to (though somewhat wider than) the theta range for the 4-item CATs (−0.73 to +1.91). Observed thetas for 12-item CATs were distributed bimodally, with low thetas ranging from −1.97 to −1.14 and high thetas were at +2.60. Twelve-item CATs only occurred when measuring extreme low and extreme high levels of Feelings of Loss-Self.

For Feelings of Loss-Person with TBI, the item bank scores vs. CAT scores correlation was 0.98 (Figure 4). The standard deviation of the differences between full item bank and CAT scores was 0.22, as was the root-mean-square deviation (RMSD) of the two score sets. The three most common CAT lengths were 4 items (n=256, 45.7%), 5 items (n=128, 22.9%), and 12 items (n=51, 9.1%); 12-item CATs were the longest CATs administered. The mean items administered for the Feelings of Loss-Person with TBI CAT was 5.7. For 4-item CATs, observed thetas ranged from −1.04 to +1.11; the theta range for 5-item CATs was similar (−1.31 to +1.35). Observed thetas for 12-item CATs were distributed bimodally: low thetas ranged from −2.39 to −1.48, while high thetas ranged from +1.70 to +2.46. That is, 12-item CATs occurred when measuring extreme low and extreme high levels of Feelings of Loss-Person with TBI.

Short Form Development.—Clinical experts selected and approved the content representativeness of the 6-item SFs of the two measures. The reliability of these SFs was examined. For Feelings of Loss-Self, score-level reliability was excellent in the theta range from −0.4 to +2.0, with expected score-level reliability ≥.90; score-level reliability in the extended theta range from −1.2 to +2.4 was very good to excellent (at least ≥.80). For Feelings of Loss-Person with TBI, score-level information was excellent in the theta range from −1.2 to +1.2, with expected score-level reliability ≥.90; score-level reliability in the extended theta range from −1.6 to +1.6 was very good to excellent (at least ≥ 80), while score-level reliability in the further extended theta range from −2.0 to +2.0 was good to excellent (at least ≥.70). Three-week test-retest for SFs was very good for both measures: for Feelings of Loss-Self, r=.87; for Feelings of Loss-Person with TBI, r=.85. Summed score to *t* score conversions for both SF measures are shown in Table 5.

Discussion

Findings supported the development of two new PROs to assess feelings of loss in caregivers of individuals with TBI: TBI-CareQOL Feelings of Loss-Self and TBI-CareQOL Feelings of Loss-Person with TBI. These new measures have several strengths. First, they were developed in accordance with established measurement development standards.[36] Second, these measures can be administered as a CAT or a 6-item SF. CAT administration minimizes participant burden without sacrificing test sensitivity, as only the most relevant and

informative items are administered to each participant. Each item is selected based on a participant's previous response until established cutoff criterion are met - either a minimum specified standard error (typically <3 on a T-score metric) or a maximum number of items administered (typically 12 items). Since the corresponding 6-item SF was developed and selected using IRT (where each individual test item can be used to generate a score), a meaningful score can be derived, which is an advantage over measures developed using classical test theory analytic approaches.

Data from this study provide additional strong psychometric support for these measures. First, reliability is supported by excellent response pattern reliability for the CAT administrations (r>.95 [37]) and internal consistency reliability for the SFs (r>.95[37]). In addition, both measures demonstrated very good 3-week test-retest reliability for the 6-item static SF (r>.85[37]).Construct validity was supported by employing defined sets of unidimensional items (as determined by both exploratory and confirmatory factor analyses). Furthermore, all items were free of DIF (i.e., there was no bias for age, education, or caregiver type: civilian vs SMV).

Study Limitations

While this study exhibits several strengths, there are limitations. First, although CAT administration is generally more efficient than traditional administration approaches, responders at either extreme end of the trait (for both Feelings of Loss-Self and Feelings of Loss-Person with TBI) will often require up to 12 items to estimate a score. Furthermore, more items will be administered in a CAT administration if responses are inconsistent. Regardless, CAT simulation data suggest that the CAT performs well for individuals with scale scores between 1.02 and +2.47 (83.9%) for Feelings of Loss-Self (i.e., for CATs with <10 items administered) and between −1.55 and +1.64 (88.9%) for Feelings of Loss-Person with TBI (<10 items administered). Although the predominance of female caregivers in our sample is consistent with other published studies [11,16,58–65], generalizability to male caregivers is uncertain. Similarly, consistent with previous studies[64,65], the majority of the SMV caregivers were spouses, which limits generalizability to parent caregivers. Finally, additional work is needed to establish more comprehensive validity data and responsiveness to change data for these measures.

Conclusions

These are the first caregiver-specific PRO measures of feelings of loss, and they are among the first CATs that have been used to evaluate HRQOL in caregivers of individuals with TBI. Additional research on these measures could focus on how the scores of these measures correlate to the caregiver's and person with TBI's emotional status and functional outcomes. Understanding these relationships could potentially identify at-risk individuals with difficulty adjusting to changes in roles and relationships after TBI. Such information could guide treatment professionals in targeting treatment for caregivers and ultimately maximize the rehabilitation process and emotional well-being of both caregivers and persons with TBI.

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List of Abbreviations:

CAT	Computer Adaptive Test
CTT	Classical Test Theory
CFA	Confirmatory Factor Analysis
CFI	Confirmatory Fit Index
DIF	Differential Item Functioning
EFA	Exploratory Factor Analysis
GRM	Graded Response Model
HRQOL	Health-Related Quality of Life
IRT	Item Response Theory
PRO	Patient-Reported Outcome
PROMIS	Patient-Reported Outcomes Measurement Information System
RMSD	Root Mean Square Deviation
RMSEA	Root Mean Squared Error of Approximation
SE	Standard Error
SF	Short Form
SMV	Service Member/Veteran
TBI	Traumatic Brain Injury
TBI-CareQOL	Traumatic Brain Injury Caregiver Quality of Life
TLI	Tucker Lewis Index

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Highlights

- Feelings of loss are common in caregivers of persons with traumatic brain injury
- Two new self-report measures of caregiver feelings of loss were developed
- These self-report measures can help identify feelings of entrapment in caregivers

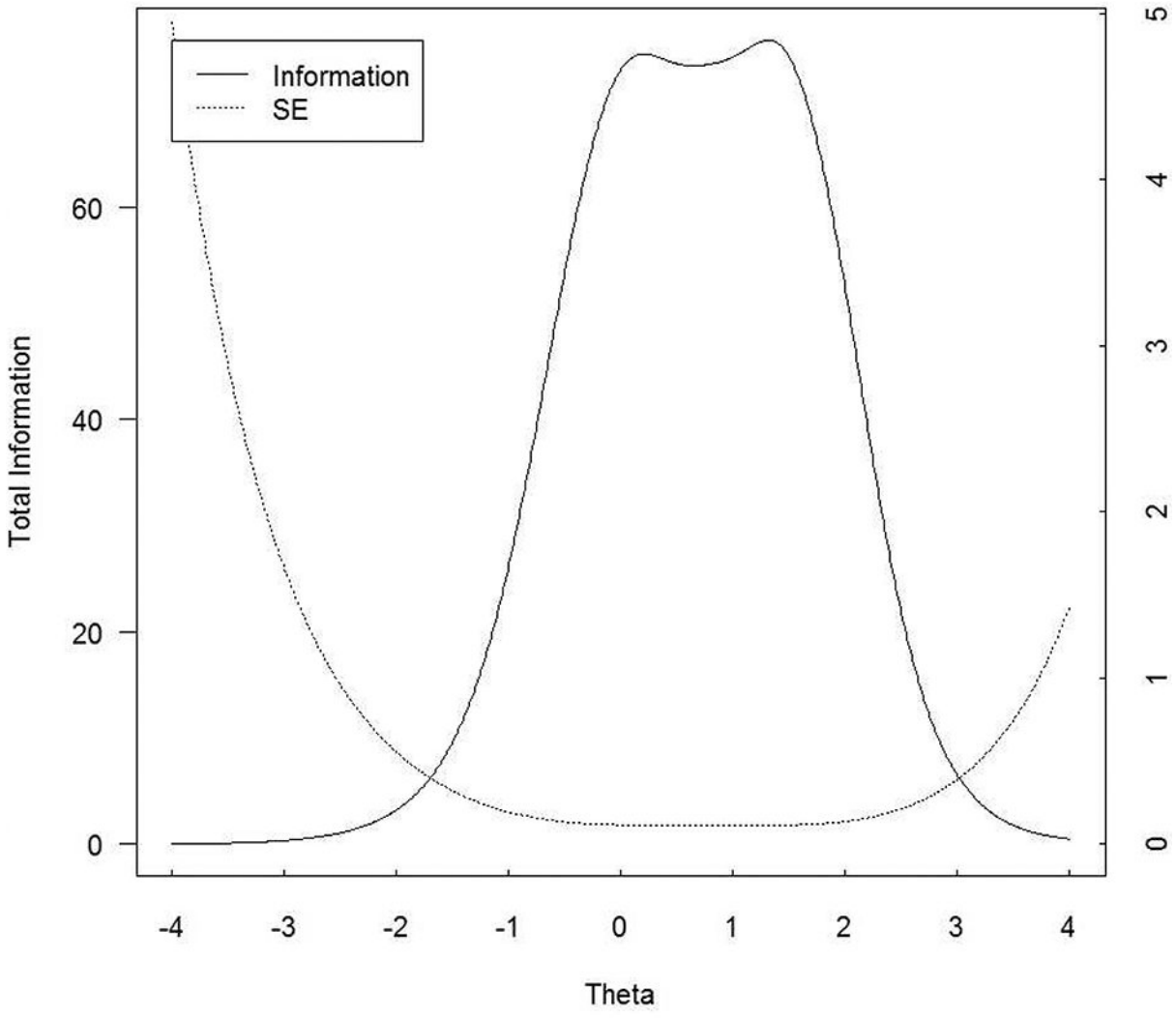

Figure 1. Feelings of Loss-Self Test Information Plot

In general, total information should be ≥ 10.0 and the standard error should be ≤ 0.32 (this provides a reliability of 0.9). This figure shows excellent total information and standard error for Feelings of Loss-Self scale scores between −1.2 and +2.8.

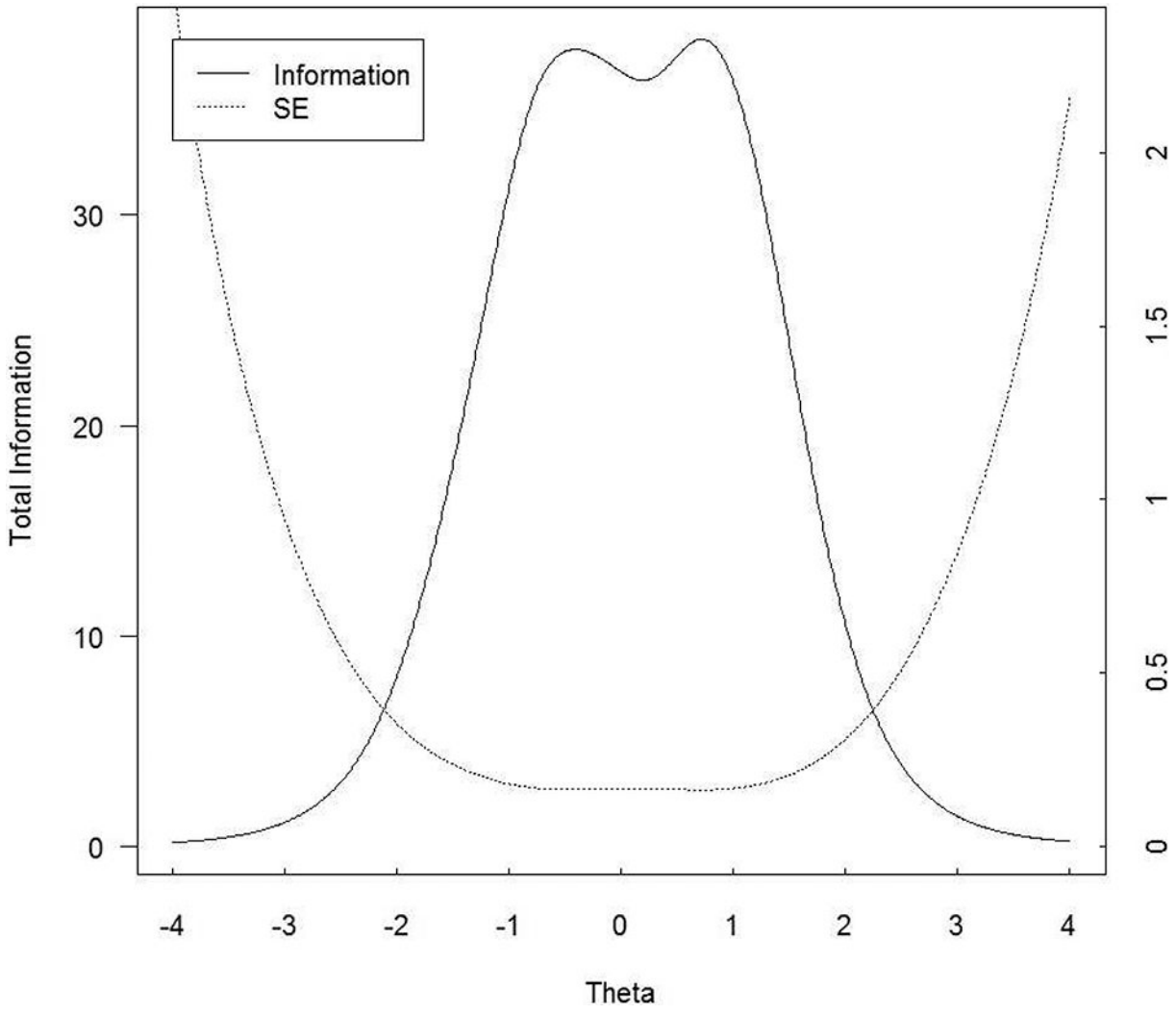

Figure 2. Feelings of Loss-Person with TBI Test Information Plot

In general, total information should be ≥ 10.0 and the standard error should be ≤ 0.32 (this provides a reliability of 0.9). This figure shows excellent total information and standard error for Feelings of Loss-Person with TBI scale scores between −1.6 and +2.0.

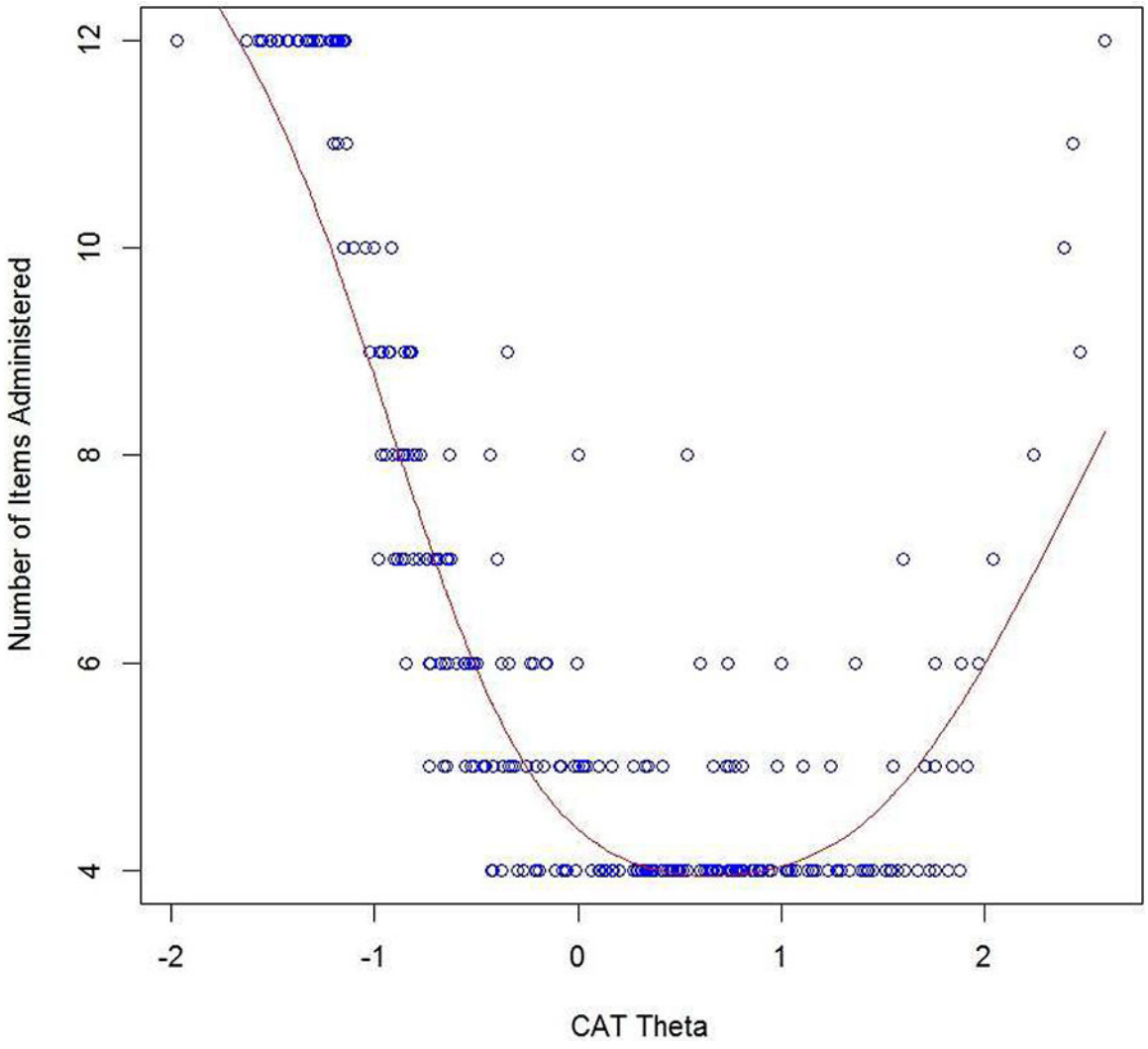

Figure 3. Feelings of Loss-Self Number of CAT Items by CAT Theta

This figure shows the number of CAT items used for different scale scores in standard deviation units: at approximately ≤−1.0 SD units and ≥+2.5 SD units the maximum of 12 items from the item bank were used by the CAT; from approximately −0.5 to +2.0 SD units the CAT tended to use the minimum of four items from the item bank.

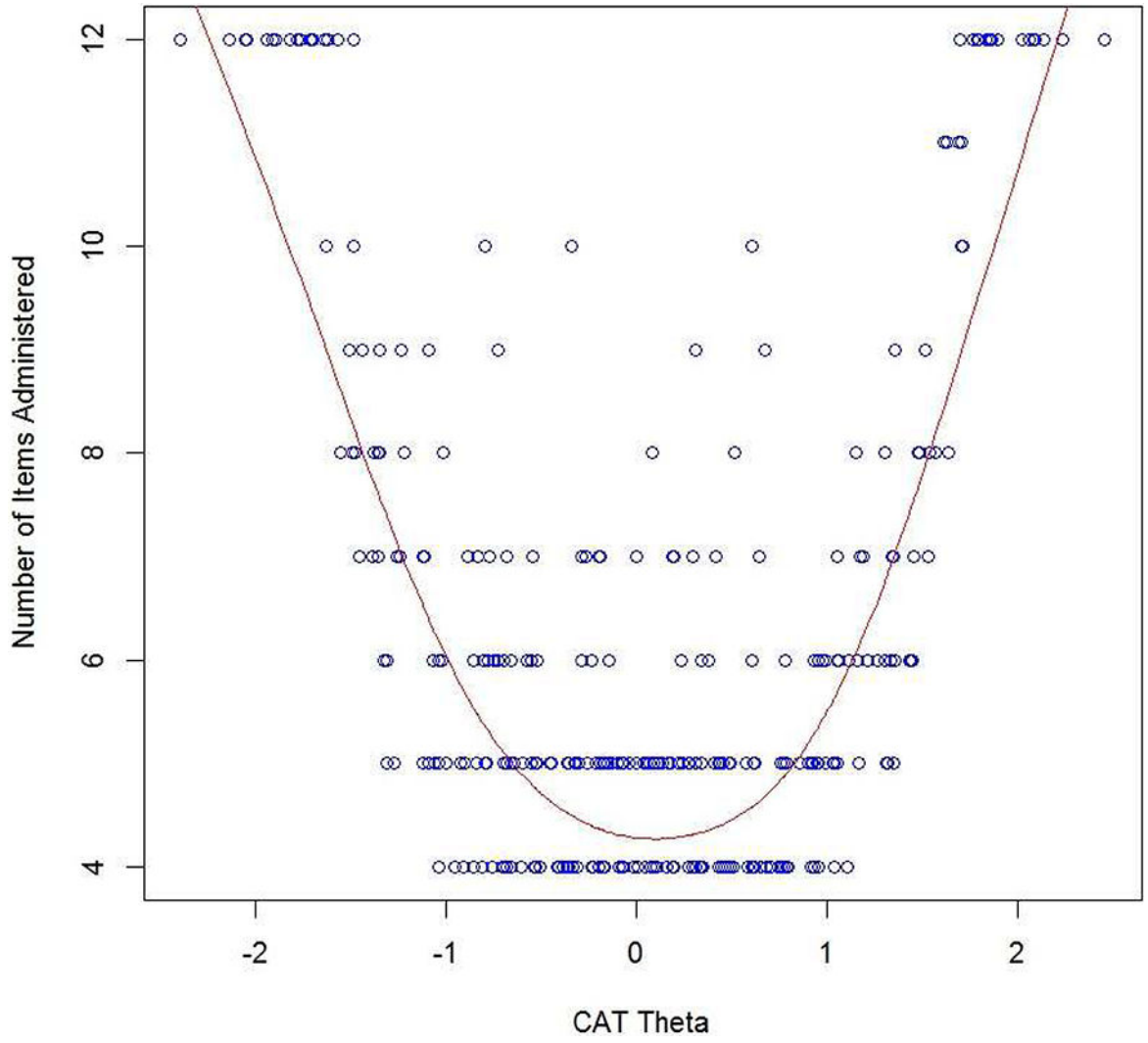

Figure 4. Feelings of Loss-Person with TBI Test Information Plot

This figure shows the number of CAT items used for different scale scores in standard deviation units: at approximately ≤−1.5 SD units and ≥+1.5 SD units the maximum of 12 items from the item bank were used by the CAT; from approximately −1.0 to +1.0 SD units the CAT tended to use the minimum of four items from the item bank.

Table 1

Exploratory Factor Analysis Results for the Feelings of Loss Item Pool

Item Description	Factor 1	Factor 2	Factor 3	Factor 4
I have stopped living my life to care for the person with the injury.	**0.72**	0.03	−0.11	0.38
It feels like I have lost my own identity because I am caring for someone else.	**0.85**	0.00	−0.07	0.33
The responsibilities I have as a caregiver make me feel socially isolated.	**0.86**	−0.06	−0.10	0.42
I am sad because my life may not be the way I thought it would be.	**0.83**	0.07	−0.01	−0.09
I feel sad I cannot go places because I have to care for the person with the injury.	**0.87**	0.01	−0.11	0.25
I mourn that I can no longer do things that I had planned because of my role as a caregiver.	**0.88**	0.01	−0.03	0.17
I mourn for the life I used to have before the person I care for was injured.	**0.76**	0.07	0.11	−0.02
I get depressed when I think that I am losing my future.	**0.96**	0.08	−0.16	−0.09
I feel devastated when I think that I am losing my future.	**0.98**	0.13	−0.22	−0.07
I feel miserable when I think about how my life has changed since the injury.	**0.86**	0.07	0.01	−0.16
I feel sad because becoming a caregiver has changed who I am.	**0.90**	−0.13	0.11	−0.02
I feel sad because I am no longer able to do things I used to enjoy with the person I care for.	**0.43**	0.22	0.35	0.04
I feel sad because becoming a caregiver has changed what I expect for my future.	**0.96**	−0.07	−0.01	0.03
I feel devastated because my plans for the future have changed since the injury.	**0.83**	0.16	−0.07	−0.08
It is difficult to pursue new relationships because I have to care for the person with the injury.	**0.70**	0.04	0.02	0.31
It is difficult to deal with personality changes in the person I care for.	**0.37**	0.24	0.31	0.04
My relationships with other people are affected because I have to care for the person with the injury.	**0.68**	0.05	0.05	0.44
I have a sense of loss due to the injury.	**0.44**	0.32	0.16	0.07
I have a sense of loss because I cannot travel as much as I would like because of my caregiver responsibilities.	**0.72**	0.07	−0.03	0.34
I miss the way my life was before the injury.	**0.72**	0.00	0.21	0.02
I feel like the plans I had for the rest of my life have changed since becoming a caregiver.	**0.77**	0.03	0.06	0.22
I have difficulty accepting how much my life has changed.	**0.79**	0.01	0.15	−0.16
I feel like I do not have a fulfilling life due to my role as a caregiver.	**0.84**	0.01	0.04	0.02
I feel that I have no hope when I think about the future of the person I care for.	**0.56**	0.36	−0.01	−0.07
I feel like the life I once had is now over.	**0.80**	0.04	0.07	0.09
I feel like my life is gone because I am providing care for someone else.	**0.89**	0.03	−0.02	0.03
It is difficult to accept my new way of life.	**0.83**	0.02	0.11	−0.18
My life has changed for the worse due to my role as a caregiver.	**0.86**	−0.01	0.01	−0.07

Item Description	Factor 1	Factor 2	Factor 3	Factor 4
I feel like I have changed the focus of my life to care for the person with the injury.	**0.46**	0.12	−0.01	0.46
It is difficult to accept that I may be caring for the person with the injury for the rest of my life.	**0.74**	0.09	0.03	−0.07
I limit my social activities because I have to care for the person with the injury.	**0.62**	0.01	0.03	0.54
I have had trouble getting my life going again since the person I care for was injured.	**0.62**	0.07	0.16	0.14
I neglect relationships because of my caregiving role.	**0.71**	−0.04	0.06	0.44
I feel excluded from social activities because I have to care for the person with the injury.	**0.72**	0.00	0.04	0.48
I feel like I do not have direction in my life.	**0.87**	−0.10	0.03	0.04
I feel like I have lost relationships because of my caregiver responsibilities.	**0.74**	−0.06	0.07	0.44
I feel like my life has been turned upside down because of the injury.	**0.66**	0.06	0.16	0.12
I feel lonely in my role as a caregiver.	**0.75**	−0.10	0.22	0.19
It feels like life is going on without me.	**0.83**	0.01	0.02	0.12
I feel as if I do not have anyone to share my life with anymore due to the injury.	**0.74**	−0.08	0.26	0.10
I feel depressed because it is difficult to relate to the person I care for.	**0.48**	0.17	0.35	−0.11
I feel like my life was ruined by the injury.	**0.79**	0.02	0.14	−0.12
I feel like my life has been destroyed by the injury.	**0.84**	0.01	0.10	−0.09
My heart breaks over the situation the person I care for is in.	0.00	**0.76**	−0.10	0.18
I mourn the way the person I care for used to be before the injury.	−0.11	**0.78**	0.23	−0.03
I get sad when I think about the loss of abilities of the person with the injury.	−0.12	**0.97**	0.04	0.07
I get sad because it is difficult to put myself in the position of the person I care for.	0.13	**0.45**	0.16	−0.12
I get sad when I think about lost relationships of the person I care for.	0.03	**0.67**	0.21	0.06
I get depressed when I think about the situation the person I care for is in.	0.22	**0.70**	−0.07	−0.10
I feel devastated when I think that the person I care for is losing his/her future.	0.21	**0.78**	−0.12	−0.06
I feel sad because the person I care for has experienced changes in emotion that are a result of the injury.	−0.11	**0.78**	0.23	0.13
I feel sad because the person I care for has experienced changes in memory that are a result of the injury.	0.02	**0.69**	0.16	0.12
I feel sad because the person I care for may never fully recover.	0.01	**0.89**	−0.03	0.10
I feel angry because the person I care for may never fully recover.	0.20	**0.66**	−0.04	−0.10
I feel as if the person I care for does not have a fulfilling life since the injury.	0.06	**0.77**	0.00	0.00
It is difficult trying to accept that the person I care for may never fully recover.	0.23	**0.60**	0.04	−0.08
It is difficult to accept that the person I care for is no longer the same person as before.	0.15	**0.53**	0.30	−0.13
It is painful to remember who the person I care for used to be before the injury.	0.01	**0.50**	0.46	−0.06
I mourn the fact that the person I care for no longer interacts with other family members in the same way as before the injury.	0.01	**0.47**	0.45	0.20

Item Description	Factor 1	Factor 2	Factor 3	Factor 4
I feel like I am grieving for who the person I care for used to be.	0.11	**0.51**	0.43	0.02
I grieve about the loss of the future of the person I care for.	0.10	**0.77**	0.07	0.03
I feel devastated about the changes in personality of the person I care for since their injury.	0.08	**0.55**	0.36	−0.08
I feel like the life of the person I care for has been destroyed by the injury.	0.22	**0.60**	0.11	0.03
I get sad when I think about how much my relationship has changed with the person I care for since the injury.	0.27	0.20	**0.53**	−0.04
I feel like I am waiting for the person I care for to change back to the person she/he used to be.	0.24	0.26	**0.27**	−0.19
I have had to adjust to the new personality of the person I care for.	0.00	0.33	**0.46**	0.20
I miss the companionship I once shared with the person I care for.	0.19	0.17	**0.64**	0.00
I feel like I need to get to know the person I care for again.	0.10	0.17	**0.60**	0.02
I mourn the fact that the person I care for no longer interacts with me in the same way as before the injury.	0.08	0.27	**0.68**	0.04
I feel like the bond I once shared with the person I care for is gone.	0.37	0.00	**0.63**	−0.08

Table 2

Unidimensional Modeling and Analyses

	Unidimensional Modeling								Initial Item Performance		IRT Modeling	
Domain	**Item pool**	**EFA E1/E2 ratio (criterion >4)**	**Percent of variance for E1 (criterion >40)**	**1-factor CFA loading (criterion <.50)**	**1-factor CFA residual correlation (criterion >.20)**	**1-factor CFA modification index (criterion >100)**	**Item-adjusted total score correlations (Criterion <.40)**	**Sparse cells (criterion<10)**	**Problems with monotonicity**	**IRT item misfit**	**LL_Q**	**Interim/Final item bank**
Caregiver Feelings of Loss-Self	43 items	--	--	0 items	0 items	0 item	0 items	0 items	0 items	13 items	0 items	30 items
Caregiver Feelings of Loss-Person with TBI	20 items	--	--	0 items	0 items	1 item	0 items	0 items	0 items	0 items	0 items	19 items

Note. CFA = Confirmatory Factor Analysis; EFA = Exploratory Factor Analysis; IRT = Item Response Theory

Table 3

Final Item Parameters

Domain	Item Bank	CFI (criterion >95)	TLI (criterion >.95)	CFA-based RMSEA (criterion < .15)	Alpha Reliability (criterion > .80)	IRT-based RMSEA (criterion < .15)	Response Pattern Reliability (criterion > .80)
Caregiver Feelings of Loss-Self	30 items	.96	.96	.10	.98	.09	.97
Caregiver Feelings of Loss-Other	19 items	.97	.97	.095	.96	.09	.96

Note. CFI = Comparative Fit Index, TLI = Tucker-Lewis Index, RMSEA: Root Mean Square Error of Approximation.

Table 4

TBI-CareQOL Item Parameters for Feelings of Loss-Self, and Feelings of Loss-Person with TBI

Item	Slope	Threshold 1	Threshold 2	Threshold 3	Threshold 4
FEELINGS OF LOSS-SELF					
I have stopped living my life to care for the person with the injury.	2.08	−0.47	0.22	1.17	1.98
It feels like I have lost my own identity because I am caring for someone else.	3.11	−0.43	0.11	0.98	1.53
The responsibilities I have as a caregiver make me feel socially isolated.	2.78	−0.50	0.03	0.83	1.52
I mourn for the life I used to have before the person I care for was injured.	3.29	−0.52	0.06	0.94	1.33
I get depressed when I think that I am losing my future.	3.29	−0.11	0.52	1.28	1.71
I feel miserable when I think about how my life has changed since the injury.	3.37	−0.25	0.42	1.28	1.70
I feel sad because becoming a caregiver has changed what I expect for my future.	3.52	−0.40	0.15	0.98	1.41
I feel devastated because my plans for the future have changed since the injury.	3.51	−0.03	0.55	1.24	1.73
It is difficult to deal with personality changes in the person I care for.	2.00	−1.45	−0.67	0.56	1.16
My relationships with other people are affected because I have to care for the person with the injury.	2.86	−0.58	0.04	0.92	1.54
I have a sense of loss due to the injury.	2.25	−0.90	−0.28	0.67	1.31
I have a sense of loss because I cannot travel as much as I would like because of my caregiver responsibilities.	2.47	−0.34	0.35	1.29	1.74
I miss the way my life was before the injury.	2.84	−0.83	−0.28	0.76	1.17
I have difficulty accepting how much my life has changed.	2.95	−0.35	0.37	1.41	1.81
I feel like I don’t have a fulfilling life due to my role as a caregiver.	3.32	−0.01	0.60	1.41	1.93
I feel that I have no hope when I think about the future of the person I care for.	2.39	0.09	0.79	1.69	2.30
I feel like the life I once had is now over.	3.50	−0.17	0.35	0.91	1.37
I feel like my life is gone because I am providing care for someone else.	3.92	0.18	0.84	1.45	1.98
It is difficult to accept my new way of life.	3.23	−0.13	0.59	1.57	2.08
My life has changed for the worse due to my role as a caregiver.	3.10	0.22	0.76	1.57	2.02
It is difficult to accept that I may be caring for the person with the injury for the rest of my life.	2.29	−0.39	0.27	1.29	1.87
I have had trouble getting my life going again since the person I care for was injured.	2.55	−0.35	0.29	1.26	1.85
I neglect relationships because of my caregiving role.	2.54	−0.58	0.00	1.04	1.64
I feel excluded from social activities because I have to care for the person with the injury.	2.76	−0.36	0.19	1.15	1.65
I feel like I don’t have direction in my life.	2.65	−0.07	0.57	1.46	2.06

Item	Slope	Threshold 1	Threshold 2	Threshold 3	Threshold 4
FEELINGS OF LOSS-SELF					
I feel like I have lost relationships because of my caregiver responsibilities.	2.76	−0.23	0.30	1.23	1.62
I feel like my life has been turned upside down because of the injury.	2.59	−0.72	−0.23	0.73	1.33
I feel lonely in my role as a caregiver.	2.91	−0.52	−0.10	0.93	1.47
I feel like my life was ruined by the injury.	3.21	0.18	0.74	1.44	1.77
I feel like my life has been destroyed by the injury.	3.63	0.09	0.66	1.37	1.75
FEELINGS OF LOSS-PERSON WITH TBI					
My heart breaks over the situation the person I care for is in.	1.67	−1.92	−1.19	0.10	0.68
I mourn the way the person I care for used to be before the injury.	2.72	−1.28	−0.73	0.33	0.84
I get sad when I think about the loss of abilities of the person with the injury.	3.24	−1.50	−0.96	0.14	0.72
I get sad because it is difficult to put myself in the position of the person I care for.	1.53	−0.84	0.11	1.32	2.12
I get sad when I think about lost relationships of the person I care for.	2.48	−0.92	−0.37	0.57	1.18
I get depressed when I think about the situation the person I care for is in.	2.57	−0.77	−0.18	0.74	1.29
I feel devastated when I think that the person I care for is losing his/her future.	3.03	−0.58	−0.04	0.73	1.17
I feel sad because the person I care for has experienced changes in memory that are a result of the injury.	2.27	−1.76	−1.24	−0.09	0.61
I feel sad because the person I care for may never fully recover.	3.05	−1.13	−0.61	0.22	0.65
I feel angry because the person I care for may never fully recover.	2.07	−0.45	0.05	0.98	1.40
I feel as if the person I care for does not have a fulfilling life since the injury.	2.47	−0.72	−0.25	0.74	1.34
It is difficult trying to accept that the person I care for may never fully recover.	2.40	−0.78	−0.18	0.86	1.36
It is difficult to accept that the person I care for is no longer the same person as before.	2.75	−0.94	−0.33	0.75	1.25
It is painful to remember who the person I care for used to be before the injury.	2.38	−0.77	−0.31	0.75	1.16
I mourn the fact that the person I care for no longer interacts with other family members in the same way as before the injury.	2.12	−0.78	−0.32	0.69	1.18
I feel like I am grieving for who the person I care for used to be.	3.08	−0.64	−0.18	0.72	1.16
I grieve about the loss of the future of the person I care for.	3.70	−0.71	−0.26	0.67	0.99
I feel devastated about the changes in personality of the person I care for since their injury.	2.77	−0.64	−0.03	0.83	1.28
I feel like the life of the person I care for has been destroyed by the injury.	2.83	−0.63	−0.18	0.59	1.14

Note. Items that are indicated in bold were selected for inclusion on the 6-item, Feelings of Loss-Self, and Feelings of Loss-Person with the TBI short forms

Table 5

Short-Form Summed Score to *t* Score Conversion Table for Feelings of Loss-Self and Feelings

	Feelings of Loss-Self		Feelings of Loss-Person with TBI	
Raw Score	**T-score**	**SE** *	**T-score**	**SE** *
6	35.24	5.38	31.14	4.96
7	40.62	3.64	35.87	3.56
8	42.79	3.39	38.08	3.38
9	44.87	2.96	40.12	3.06
10	46.47	2.79	41.71	2.95
11	47.93	2.63	43.20	2.82
12	49.27	2.54	44.54	2.77
13	50.55	2.48	45.82	2.74
14	51.78	2.44	47.05	2.73
15	52.97	2.41	48.26	2.73
16	54.13	2.39	49.44	2.74
17	55.27	2.38	50.61	2.74
18	56.38	2.37	51.75	2.74
19	57.48	2.36	52.90	2.73
20	58.57	2.34	54.03	2.73
21	59.65	2.33	55.17	2.72
22	60.72	2.32	56.32	2.72
23	61.81	2.32	57.48	2.73
24	62.92	2.34	58.69	2.78
25	64.07	2.37	59.93	2.84
26	65.31	2.43	61.31	3.02
27	66.66	2.54	62.70	3.13
28	68.25	2.76	64.59	3.52
29	70.12	2.96	66.19	3.63
30	74.11	4.16	70.31	4.82

*SE = Standard error