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Psychological well-being in individuals living in the community with traumatic brain injury

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Abstract

Background: Well-being and quality of life issues remain a long-term problem for many individuals with traumatic brain injury (TBI). Meaningful activity is key to developing life satisfaction and a sense of contribution to society, yet individuals with TBI are often unable to return to competitive employment.

Objective: To describe the self-reported psychological well-being of a cohort of unemployed individuals living in the community at least 1 year post TBI with low life satisfaction.

Methods: Seventy-four unemployed individuals with low life satisfaction at least 1 year post TBI were administered measures of psychological well-being and cognitive functioning.

Results: This cohort of 74 participants demonstrated cognitive impairment and elevated levels of emotional distress. Significant bivariate relationships were noted among nearly all measures of well-being, and associations were in the directions as expected. Individuals reported low life satisfaction and well-being. Two newer measures of well-being correlated with established measures used with this population.

Conclusions: Individuals with TBI living in the community who are not employed but who seek to be productive reported low life satisfaction and well-being. This study highlights the need for interventions aimed at increasing productivity and meaning in life for individuals with TBI, and a broader understanding of psychological health after TBI.

Keywords

TBI; psychological well-being; productivity

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Declaration of Interest

The authors have no declarations of interest to report.

Introduction

A primary goal of comprehensive rehabilitation after traumatic brain injury (TBI) is returning individuals to healthy, productive and satisfying lives (1,2). These dimensions of well-being are considered indicators of adjustment to disability and should be a major focus of rehabilitation (1–3). TBI can affect every aspect of an individual's life, disrupting physical, cognitive, emotional and social functioning. Depression, anxiety and decreased productivity are common sequelae of TBI (4,5). Individuals with TBI are often unable to resume pre-injury social and vocational roles, and such role loss has been associated with a diminished sense of purpose in life (6–8). Well-being and quality of life issues remain a long-term problem for many individuals with TBI (9).

Life satisfaction, positive and negative emotions, social relationships and purpose in life are all essential components of well-being (10–12). Meaningful, productive activity is key to developing life satisfaction and a sense of contribution to society, and often provides an avenue for social interaction (13–15). A recent study indicated a relationship between social integration and life satisfaction in individuals with TBI (16). Yet, individuals with moderate-to-severe TBI are often unable to return to competitive employment, with return to work rates reported as low as 30% (17–20). Many individuals living with TBI spend a majority of their time in non-productive activities and spend more time alone than individuals without TBI (21). Social isolation and loneliness are major issues for this population (21,22). Post-injury psychological distress is common with estimates of anxiety disorders ranging from 11% to 70% and depressive disorders ranging from 25% to 42% (4,5). The combination of diminished productivity, social isolation and psychological issues can make well-being elusive for individuals post TBI (23). Long-term costs of impaired well-being post TBI are realised through lost relationships, decreased productivity and lowered self-esteem for the individual and family, as well as the financial costs of ongoing therapy and services (24).

Recent literature regarding the components of well-being has suggested that additional factors should be explored, including social capital and social-psychological prosperity (11,25). Successful social relationships have been defined as receiving the support of others, but more recently it has been hypothesised that people also need to support others as part of relationship success (25). The Flourishing Scale (FS) was developed to complement existing measures of well-being by adding components of relationships, prosperity, competence, meaning and purpose in life. Positive and negative emotions are another important component of well-being, but there has been criticism of the available measures (25). The Scale of Positive and Negative Emotion (SPANE) was developed to frame positive and negative emotions in terms of the time that an individual experiences a specific feeling, which is more closely related to well-being measures such as life satisfaction (7).

The purpose of this study was to describe a cohort of unemployed individuals living in the community at least 1 year post TBI who were interested in improving their psychological well-being, and to investigate the associations among self-described well-being measures within this particular cohort.

Methods

This study was approved by the site's institutional review board, and all participants provided written informed consent. The data used for this study were collected as baseline data as part of a longitudinal randomised controlled trial (RCT) investigating the efficacy of a novel structured intervention facilitating altruistic volunteer activity to improve well-being in individuals with TBI.

Participants

The study included individuals with TBI who were able to navigate independently in the community and were not employed or volunteering. Participants were enrolled in a study testing a volunteer intervention post TBI, and therefore were individuals interested in taking part in volunteer activity to improve psychological well-being. Specific inclusion and exclusion criteria are outlined in Table 1.

Procedure

This research took place at a rehabilitation hospital specialising in the treatment of individuals with TBI or spinal cord injury. Recruitment letters were mailed to former patients with TBI and recruitment materials were provided to members of local area organisations serving people with TBI.

Telephone screening—Individuals who expressed interest in the RCT study took part in a telephone screening consisting of a structured interview regarding the inclusion and exclusion criteria. The Supervision Rating Scale (26) was used as a screening measure to assess level of independent functioning. Those meeting the criteria were invited to come in person to provide written informed consent for participation in the study. Two-hundred and forty-four people were screened for participation in this study; 170 of those did not meet inclusion/exclusion criteria. The remaining 74 meeting inclusion criteria were enrolled in the study.

Baseline data collection—Once informed consent was obtained, participants completed a baseline assessment consisting of a demographic questionnaire, an assessment of cognitive functioning and subjective measures of well-being.

Study measures

Demographic and injury characteristics.: Demographic characteristics were collected by interview with each participant at the time of enrolment. This information included age, gender, race/ethnicity, marital status, living situation, socio-economic status and education. Additionally, injury characteristics were collected and consisted of date of injury and injury aetiology.

Cognitive functioning.: Cognitive functioning was assessed using several core tests from the NIH TBI Common Data Elements Project (27) to characterise the cognitive status of participants. This testing was used to measure functional severity level, as this group consisted of individuals with chronic TBI. These tests evaluated cognitive processing speed,

visual sequencing speed and auditory–verbal memory. Each of these assessments has well-established reliability and validity, and each has been used in previous studies of individuals with TBI (27).

The Wechsler Adult Intelligence Scale III (WAIS-III) – Processing Speed Index (WAIS III: PSI) (28,29) consists of two paper-and-pencil subtests from the WAIS-III. The Digit Symbol subtest is a timed, written symbol to digit coding test. The Symbol-Search is a timed symbol cancellation test. Both subtests have high reliability and have been validated on TBI samples (28). The Trail Making Test (TMT) (30) consists of two timed, paper-and-pencil visual sequencing tests, TMT Part A (numerical sequencing speed) and Part B (divided attention and alphanumerical sequencing speed). The TMT has adequate reliability and has been validated on TBI samples (28). The Rey Auditory Verbal Learning Test (RAVLT) (31) is a 15-word list learning test with 5 learning trials, a post-interference word recall trial and a delayed recall trial. The RAVLT has adequate reliability and has been validated on TBI samples (28). The Medical Symptom Validity Test (MSVT) (32) is a computerised word recognition memory test that also measures if sufficient effort was made for the memory scores to be valid. The MSVT has been cross-validated against other tests of effort and memory, and is widely used in TBI (32).

Measures of Self-Reported Well-being.: The Brief Symptom Inventory-18 (BSI-18) (33) is an 18-item, self-rated, 0–4-point Likert scale of psychological distress which yields the Global Severity Index (GSI), as well as Somatic, Anxiety and Depressive dimension scores. A GSI score of 63 or higher, or any two-dimensional *T*-scores of 63 or higher, indicates a positive risk of emotional distress. The BSI-18 has strong reliability and validity among individuals with TBI (34).

The Satisfaction with Life Scale (SWLS) (10) is a 5-item, 1–7-point Likert scale of global life satisfaction which is described as a cognitively driven component of subjective well-being. Higher scores are indicative of greater life satisfaction. This scale has high internal consistency and temporal reliability (10), and has been validated in persons with TBI (35). The TBI Model Systems National Data and Statistical Center (NDSC) reports a mean SWLS score of 21.26 (standard deviation [SD] = 8.24) at 1 year post injury and 21.57 (SD = 8.39) at 2 years post injury for individuals enrolled in the TBI Model Systems (TBIMS) National Database (36).

The FS (25) is a brief 8-item, self-rated, 1–7-point Likert scale measure of self-perceived success in areas such as social relationships, feelings of competence, and meaning and purpose in life. It has good internal consistency, moderately high temporal reliability, and provides a single psychological well-being score that has been supported in factor analysis and that correlates well with other measures of well-being (25). Scores range from 8 to 56 with higher scores signifying that the individual views himself in positive terms in an area of functioning. Norms are currently available on college students with a mean of 44.97 (SD = 6.56).

The Rivermead Post Concussive Symptom Questionnaire (RPQ) (37) is a 16-item, self-report scale of common post-concussive symptoms experienced in the prior 24 hours. The

RPQ assesses the degree of symptom severity on a Likert scale: 0 = not experienced at all, 1 = no more of a problem than before injury, 2 = a mild problem, 3 = a moderate problem and 4 = a severe problem. A total score is derived by summing all scores with ratings of two or more. Thus, higher scores indicate a higher level of symptom burden. It has high-reported reliability and has been validated on individuals with TBI (37,38).

The SPANE (25) is a brief 12-item, self-rated, 1–5-point Likert scale that evaluates positive and negative emotions. It produces a score of positive feelings (6 items) and negative feelings (6 items) both ranging from 6 to 30 that can be combined by subtracting the negative from the positive, resulting in a balance score (SPANE-B). The resulting SPANE-B can range from −24 to 24. Norms are available on college students with a mean of 22.05 (SD = 3.73) for positive feelings, 15.36 (SD = 3.95) for negative feelings, and 6.69 (SD = 6.88) for the balance score. This scale has been shown to have good internal consistency, moderately high temporal reliability, and correlates with other subjective feeling measures (25,39).

The Purpose in Life subscale is one of six in the Ryff Scale of Psychological Well-Being-54 item version (11) and consists of nine, self-rated, 1–6-point Likert scale items addressing goals, sense of direction, meaning, etc. A higher score indicates that the individual has increased well-being, with a sense of direction and meaning in life, and has aims and objectives for living. This subscale was selected as part of the RCT study because volunteering has been shown to have a positive relationship with a sense of purpose in life (40). Additionally, in a small pilot study conducted prior to the RCT, participants showed improvement on this subscale and appeared to comprehend the items, whereas items on the other Ryff subscales seemed too abstract. The Purpose in Life subscale has been shown to have adequate reliability (41).

Statistical analysis

The demographic and injury characteristics of the sample were summarised with means and SD for continuous normally distributed variables, medians and interquartile ranges (IQR) for skewed continuous variables, and frequency counts and percentages for nominal variables. The neuropsychological functioning and self-reported well-being measures were summarised for this sample using similar methods. Neuropsychological functioning and BSI measures were summarised using standardised *T*-scores (mean = 50, SD = 10). Subjects with *T*-scores less than 1 SD of the standardised mean (*T*-score < 40) were considered to be impaired on the neuropsychological measures. Similarly, subjects with *T*-Scores greater than 1 SD of the standardised mean (*T*-scores > 60) were considered impaired on the BSI measures. In addition, positive risk for emotional distress on BSI was defined as a GSI score of 63 or higher, or any two-dimensional *T*-scores of 63 or higher. The pairwise relationship among the measures was assessed using Pearson correlation coefficient (*r*). SAS v.9.4 (42) was used for all data analyses and a significance level of 0.05 was assumed for all statistical tests.

Results

Demographic and injury characteristics

The demographic characteristics of the 74 participants are summarised in Table 2. Participants were on average 48.1 years of age (SD = 11.8), primarily white (73%), employed or full-time students pre-injury (85.2%), currently earning less than $50,000 annually (72.1%) and living in a private residence (97.3%). The majority had some level of college education (44.6% with some college education, 31.1% with a bachelor's degree or above). The median time since injury was 5.5 years (IQR = 2 – 17). A slightly higher number of females than males took part in the study (51.4%).

Cognitive functioning and emotional well-being

Results for standardised measures of cognitive functioning and the BSI-18 are presented in Table 3. Percentile rank represents how individuals in this sample perform relative to the normative sample (mean = 50, SD = 10). Participants in this sample demonstrated significant cognitive impairment relative to the normative sample with 25–54% of participants having *T*-scores 1 SD below the mean (expected 16.5%) and 7–30% of participants having *T*-scores 2 SD below the mean (expected 2.5%). This sample also demonstrated high levels of emotional distress relative to the normative sample with 45–57% having *T*-scores 1 SD above the mean (expected 16.5%) and 12–16% having *T*-scores 2 SD above the mean (expected 2.5%).

Descriptive statistics for the other measures of well-being are shown in Table 4. The mean score for SWLS was 16.1 (SD = 6.7), which is notably lower than the reported average for TBIMS National Database participants. In terms of post-concussive symptomology, 93% of participants endorsed at least one of the 16 RPQ items at a moderate level and 69% endorsed at least one at a severe level, compared to before their injury.

The pairwise correlations among the cognitive and emotional well-being outcome measures are summarised in Table 5. There were significant bivariate relationships among nearly all measures, and associations were in the directions as expected.

Discussion

Participants in this study were well-educated and mostly employed or in school at the time of injury. However, at an average of five and a half years post injury, they were not working or volunteering in the community. Participants showed impairments in cognition and psychological well-being across several measures, as is typical for this population. Cognitive screening indicated that half of this sample exhibited slow processing speed and memory difficulties. Three quarters of the group exhibited problems with performing sequential procedures. This sample represents individuals with chronic TBI who are no longer involved in the productive activity that once characterised their lives.

Half of the participants in this study were female. This finding is unusual as 1.4 times as many TBIs occur among males as among females (43) and the majority of participants in previous studies at this facility have been male. The increased number of female participants

could be because participants were interested in taking part in volunteer activity, and in general women are more motivated than men to volunteer (44).

This sample noted problems with psychological well-being across all measures, including life satisfaction, mood, affect, self-perceived success, purpose and meaning in life. SWLS scores were lower in this group than the norm for TBI. Participants were not working or volunteering and therefore not involved in productive activity. Results for the FS and the SPANE, two relatively new measures of well-being which have not been used before with this population, correlated with other established measures of well-being. The FS and SPANE allow for a more detailed assessment of well-being by adding components of social capital and social-psychological prosperity, as well as positive and negative emotions. These correlate well with the SWLS, which is frequently used with this population, allowing us to ascertain a broader understanding of well-being following TBI. However, it should be noted that this cohort excluded individuals with high life satisfaction.

Even though this sample exhibited problems with psychological well-being, participants took the initiative to enroll in a study aimed at improving their well-being. This desire or drive is notable given the common difficulty with decreased initiation in this population.

Conclusion

This study recruited individuals with TBI who are living in the community, not employed and who reported low life satisfaction. These individuals showed decreased psychological well-being across study measures. Additional measures of well-being (FS and SPANE), allowing a broader view of well-being, can be added to the repertoire of assessment tools to be used among individuals with TBI.

Future research should investigate the drive and motivation required to take part in productive, meaningful activity even in light of the challenges of living with chronic TBI. More importantly, future research should explore the efficacy of interventions aimed at increasing satisfaction with life and other measures of psychological well-being. These interventions should take into consideration the possible role of productive activity in psychological well-being. There is also a need for normative data on these measures of psychological well-being with this population.

Limitations

This was a convenience sample of individuals who met the criteria for a larger study. This study only included individuals with an SWLS of 25 or below, excluding those with higher than average satisfaction with life. Valid MSVT results were found for 80% of the sample, suggesting that approximately 20% of the sample may not have produced valid performance. The entire sample was retained for analysis to characterise individuals with TBI who volunteer for research. *T*-scores for these subjects may suggest that subjects are more impaired then they really are.

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Table 1.

Inclusion and exclusion criteria.

Inclusion Criteria
• Sustained a TBI as defined by damage to brain tissue caused by an external mechanical force as evidenced by loss of consciousness or post-traumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination
• Able to provide documentation of TBI either by medical records or a written confirmation by a licensed health-care provider qualified to make the diagnosis
• Received inpatient or outpatient TBI rehabilitation treatment
• At least 1 year post TBI
• Age 18 or older
• Able to commit to completing the entire 3-month volunteer placement
• English or Spanish speaking
• Rated a level 1–2 on the Supervision Rating Scale (functionally independent during the day)
• Provides informed consent to participate
Exclusion Criteria
• Employed or engaged in regularly scheduled volunteer work outside of the intervention for more than 3 weeks during the study
• Score of 25 or above on the SWLS (0.5 SD above the TBI Model Systems National Data Base mean) indicating an already high level of satisfaction with life
• Unable to travel to assessments and placement; even with study transportation assistance;
• Completed the pilot study of this intervention
• Cognitive impairment that precludes completion of baseline testing
• Any reason that in the opinion of the principal investigators might interfere with completion of the protocol

Table 2.

Demographic and injury characteristics.

Continuous variables	***N***	**Mean (SD)/median (IQR)**
Current age, mean (SD)	74	48.1 (11.8)
Years since injury, median (IQR)	74	5.5 (2.0–17.0)
Nominal Variables	***N***	**Percent**
Gender		
Female	38	51.4
Male	36	48.7
Race/ethnicity		
White	54	73.0
Hispanic	12	16.2
Asian/Pacific Islander	3	4.1
Native American	2	2.7
Other	3	4.1
Level of education		
Less than HS	7	9.5
HS	11	14.9
Some college	33	44.6
Bachelor’s degree or higher	23	31.1
Employment status at injury		
Employed full-time	47	63.5
Employed part-time	7	9.5
Student full-Time	9	12.2
Taking care of house or family	1	1.4
Retired	1	1.4
Unemployed (looking)	5	6.8
Other	4	5.4
Current marital status		
Single	24	32.4
Married	23	31.1
Divorced	27	36.5
Household income		
Less than $25 000	38	55.9
$25 000-$49 999	11	16.2
$50 000-$99 999	9	13.2
$100 000-$199 999	5	7.4
$200 000 or more	5	7.4
(Missing)	(6)	
Current living situation		
Alone	27	36.5
Spouse/significant other	23	31.1

Parent(s)	17	23.0
Roommate(s) or friend(s)	5	6.8
Other relative(s) or adult child(ren)	2	2.7
Current residence		
Private	72	97.3
Adult home	2	2.7
Cause of injury		
Motor vehicle	31	41.9
Motorcycle	15	20.3
Fall	11	14.9
Bicycle	5	6.8
Hit by falling/flying object	3	4.1
Pedestrian	2	2.7
Violence (gunshot, assault, other)	4	5.4

SD = standard deviation; IQR = interquartile range.

Table 3.

Cognitive functioning and BSI-18 outcomes measured at baseline.

	N	Mean	SD	Percentile rank	Impairment (1 SD)	Impairment (2 SD)
BSI-18 anxiety *T*-Score	74	58.1	12.8	79%	33 (44.6%)	12 (16.2%)
BSI-18 depression *T*-Score	74	59.7	10.7	83%	41 (55.4%)	10 (13.5%)
BSI-18 somatic *T*-Score	74	59.7	10.9	83%	42 (56.8%)	12 (16.2%)
BSI-18 Global Severity Index *T*-Score	74	61.3	10.0	87%	38 (51.4%)	9 (12.2%)
WAIS III coding *T*-Score	72	39.4	8.8	15%	33 (45.8%)	5 (6.9%)
WAIS III symbol search *T*-Score	72	44.1	9.4	27%	18 (25.0%)	7 (9.7%)
WAIS III processing index *T*-Score	72	41.1	8.9	18%	32 (44.4%)	8 (11.1%)
Trails A time *T*-Score	73	38.4	14.9	13%	36 (49.3%)	20 (27.4%)
Trails B time *T*-Score	72	38.8	14.4	13%	39 (54.2%)	14 (19.4%)
RAVLT learning total *T*-Score (Trials I-V)	71	45.1	14.8	31%	22 (31.0%)	11 (15.5%)
RAVLT immediate recall *T*-Score (Trial VI)	71	41.7	16.0	20%	30 (42.3%)	21 (29.6%)
RAVLT delayed recall *T*-Score	70	45.1	14.6	31%	26 (37.1%)	10 (14.3%)

T-scores assume a mean of 50 and SD of 10; higher scores indicate more impairment for BSI-18 measures and lower scores indicate more impairment for cognitive measures; impairment (1SD) indicates the percentage of subjects with *T*-scores <40 (cognitive measures) or >60 (BSI-18 measures); impairment (2 SD) indicates the percentage of subjects with *T*-scores <30 (cognitive measures) or >70 (BSI-18 measures). In addition, 34/74 (45.9%) have GSI above 63 OR any two-dimensional scores >63 (anxiety, depression, somatic).

Table 4.

Self-reported well-being measured at baseline.

	N	Mean	SD
Satisfaction with life	74	16.1	6.7
Flourishing scale	74	38.0	8.7
RPQ 16 item	72	32.0	15.2
Negative experience	74	16.1	5.1
Positive experience	73	20.2	4.8
Balance (positive-negative)	73	4.2	8.6
Purpose in life (Ryff)	72	29.1	4.9

Table 5.

Pairwise associations among well-being measures.

	Rivermead 16 item	Flourishing	Satisfaction with life	BSI anxiety	BSI depression	BSI somatic	BSI GSI	SPANE negative	SPANE positive	SPANE balance
Rivermead 16 item										
Flourishing	−0.30†									
Satisfaction with life	−0.20	0.56†								
BSI anxiety	0.67†	−0.31†	−0.23							
BSI depression	0.32†	−0.49†	−0.35†	0.63†						
BSI somatic	0.66†	−0.30†	−0.21	0.54†	0.42†					
BSI GSI	0.67†	−0.43†	−0.32†	0.88†	0.81†	0.75†				
SPANE negative	0.52†	−0.41†	−0.32†	0.69†	0.65†	0.36†	0.69†			
SPANE positive	−0.36†	0.62†	0.48†	−0.44†	−0.61†	−0.28†	−0.52†	−0.53†		
SPANE balance	−0.50†	0.58†	0.44†	−0.64†	−0.71†	−0.39	−0.69†	−0.88†	0.87†	
Purpose in life (Ryff)	−0.27†	0.48†	0.26†	−0.42†	−0.53†	−0.28†	−0.50†	−0.38†	0.48†	0.48†

†indicates *p*-value <0.05.