

Perceived health, caregiver burden, and quality of life in women partners providing care to Veterans with traumatic brain injury

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Abstract—Families of Veterans with traumatic brain injury (TBI) are often faced with providing long-term informal care to their loved one. However, little is known about how their perceived health and caregiving burden contribute to their quality of life (QOL). The purpose of this descriptive study was to describe perceived health, somatic symptoms, caregiver burden, and perceived QOL and to identify the extent to which these variables are associated with QOL in female partners/spouses of Veterans with TBI. Participants completed a written questionnaire including the general health subscale of the 12-Item Short Form Survey version 2, the Patient Health Questionnaire-15, Caregiver Reaction Assessment, and Quality of Life Index. Caregivers reported moderate levels of QOL, and over a quarter of the sample reported high levels of somatic symptoms, particularly fatigue and sleep disturbance. Age, perceived general health, somatic symptoms, the five subscales of caregiver burden (self-esteem, disrupted schedule, effect on finances, lack of family support, and effect on health) predicted QOL and explained 64% of its variance (adjusted $r^2 = 0.64$, $F(8,31) = 9.59$). However, only somatic symptoms and the caregiver burden subscales of self-esteem and effect on finances were significant predictors in the model. These findings have implications for development of family-centered interventions to enhance the QOL of informal caregivers of Veterans with TBI.

Key words: brain injuries, caregiver burden, caregiving, fatigue, informal caregiver, perceived health, quality of life, somatic symptoms, stress, Veterans.

INTRODUCTION

Traumatic brain injury (TBI) is considered the “signature” injury of recent U.S. conflicts, with more than 320,344 U.S. military service personnel diagnosed with TBI in the past 16 yr [1]. Consequences of moderate and severe TBI can be debilitating and include seizures, muscle spasticity, coordination difficulties, and low muscle

Abbreviations: CHD = coronary heart disease, CRA = Caregiver Reaction Assessment, PHQ-15 = Patient Health Questionnaire-15, QLI = Quality of Life Index, QOL = quality of life, SF-12 = 12-Item Short Form Health Survey, TBI = traumatic brain injury, VA = Department of Veterans Affairs.

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strength, as well as significant cognitive problems such as loss of memory, impaired communication, personality changes, and deficits in information processing [2]. In a recent study of patients with severe TBI, researchers found that 59.1 percent reported personality changes after the injury [3]. Mild TBI can also cause debilitating conditions such as attentional impairments [4]. It is not uncommon for difficulties after TBI to last 10 yr or more [5–6].

The term “informal caregiver” refers to those who provide care and assistance without pay to someone who is ill or disabled [7]. Although research has consistently demonstrated that informal caregivers are at risk for emotional and physical health problems [8–9], those caring for individuals with cognitive disabilities (such as those associated with TBI) may be at particular risk for negative emotional outcomes including depression, grief, anxiety, and decreased quality of life (QOL) [10–11]. Compared with noncaregivers, informal caregivers also report more frequent health problems and somatic symptoms (e.g., fatigue, headache, and low back pain) and take more medications [12–13]. Furthermore, those caring for persons with TBI report greater caregiver burden and worse mental health than caregivers of individuals with dementia [14]. Female caregivers are at particular risk for suffering stress-related health problems associated with caregiving [15–16]. Informal caregivers of Veterans face unique challenges associated with caring for a Veteran who may have also survived other traumatic injuries [17], placing the Veteran at higher risk for comorbidities such as depression and posttraumatic stress disorder [18]. Paradoxically, it is well established that higher levels of caregiver burden and stress are associated with poorer neuropsychological functioning and well-being of the persons with TBI [19–20]. However, studies examining the experience of informal caregivers of persons with TBI are relatively sparse compared with those of caregivers of individuals with more common diagnoses such as dementia and cancer. While the majority of informal caregivers are female [21] and almost a third of those providing care to Veterans with TBI are a spouse or partner [17], there are few studies that have specifically examined the health and well-being of wives or female partners providing care to Veterans with TBI. In light of the paucity of published evidence, it is not surprising that little is known about how caregiver burden relates to health and QOL in female partners caring for a Veteran with TBI. Since wives/partners providing care to

Veterans with TBI are significantly younger than partners of individuals with dementia or other disease processes more prominent in the elderly, they may be particularly vulnerable to the longer-term effects associated with informal caregiving. A clearer understanding of the health and QOL of TBI informal female caregivers is essential in providing the foundation for developing effective and tailored interventions to support informal caregivers and to provide family-centered care [22]. This pilot study addressed this knowledge gap by addressing these aims: (1) describe perceived health, medication use, somatic symptoms, caregiver burden, and perceived QOL for female caregivers of Veterans with TBI and (2) identify the extent to which perceived health, somatic symptoms, and caregiver burden predict QOL in female caregivers of male Veterans with TBI.

METHODS

Design and Participants

This pilot study was part of a larger study conducted to examine chronic stress in female partners providing informal care to Veterans with TBI. A cross-sectional, correlational design was used to examine perceived general health, somatic symptoms, caregiver burden, and perceived QOL among female caregiving partners of Veterans with TBI. Forty wives or female partners caring for a male Veteran with TBI were recruited nationally (**Figure**). They were recruited via letters mailed to Veterans with TBI from the local Department of Veterans Affairs (VA) facility asking the caregivers to complete a questionnaire. Recruitment was also conducted using social networking websites, such as the local VA Facebook page, and at the polytrauma outpatient clinic of a midwestern VA hospital. Individuals who were interested in the study were asked to contact the study team. Inclusion criteria for participants were (1) female, (2) aged 18 yr or older, and (3) wife or female partner caring for a male Veteran who experienced a TBI within the past 3 mo to 10 yr. Participants were also required to be able to understand, speak, and write English.

Measures

Participants self-reported demographic variables including age, marital status, highest education level (at least some college or no college), race (white or non-white), and annual household income (less than or greater than \$75,000). In addition, participants estimated the

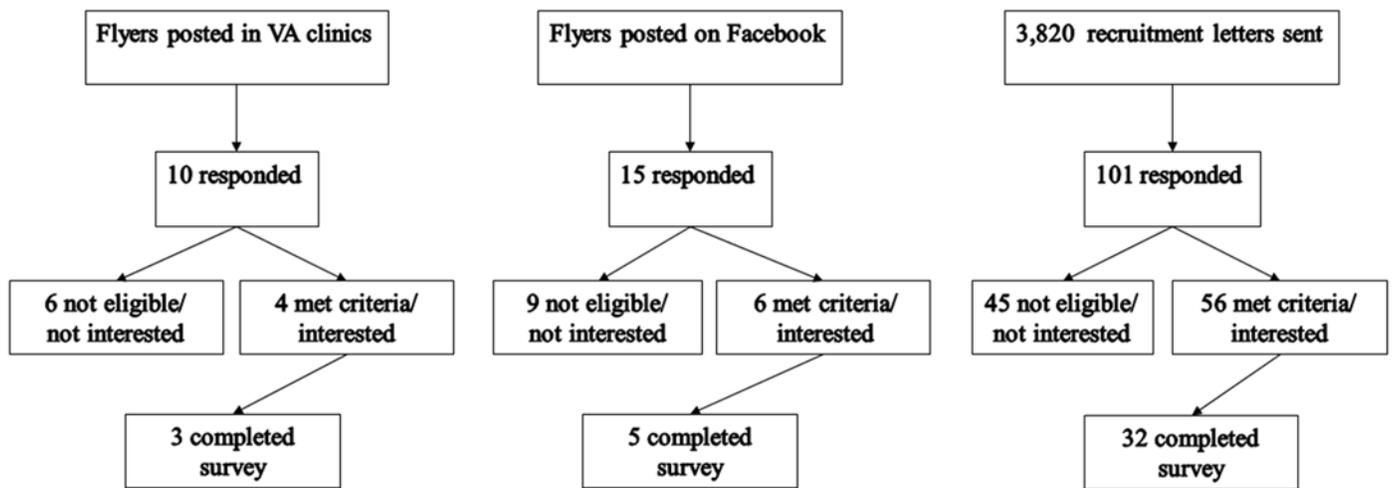


Figure.
Recruitment strategy for study. VA = Department of Veterans Affairs.

number of months they had provided care and the number of hours per week they currently provided care to their loved one. Participants also identified any current health conditions on a checklist of common health conditions and provided a list of their current medications, including both prescription and nonprescription medications.

Perceived General Health

The single general health item of the 12-Item Short Form Health Survey (SF-12) version 2 [23] was used to assess perceived overall general health. Using a Likert-type scale ranging from 1 (excellent health) to 5 (poor health), participants respond to the question, “How would you rate your general health?”

Somatic Symptoms

The Patient Health Questionnaire-15 (PHQ-15) was used to measure somatic symptoms [24]. The PHQ-15 is composed of 15 somatic symptoms, such as headache, palpitations, and backache, and each symptom is scored from 0 (“not bothered at all”) to 2 (“bothered a lot”). Total score for the PHQ-15 ranges from 0 to 30, with higher scores reflecting more bothersome somatic symptoms. Cut-off scores of 5, 10, and 15 represent low, medium, and high levels of somatic symptoms, respectively [24]. Cronbach alpha is reported to be excellent at 0.80 in a previous study of patients in a family practice clinic [24]. Cronbach alpha for this study was similar at 0.79.

Caregiver Burden

The Caregiver Reaction Assessment (CRA) [25] was used to measure caregiver burden. The CRA contains 24 items that ask caregivers to indicate their level of agreement with statements using a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). The CRA measures five aspects of burden: effect on the caregiver’s self-esteem, effect on schedule, effect on finances, lack of family support, and effect on health. Effect on the caregiver’s self-esteem is the extent to which the individual values caregiving and finds it to be rewarding. Effect on schedule measures the extent to which caregiving interrupts usual activities and interferes with relaxation time. Effect on finances examines the extent to which caregiving puts a strain on finances. The lack of family support subscale includes items that measure the extent to which the caregiver feels “dumped on” or abandoned by relatives. The fifth subscale, effect on health, assesses caregiver’s physical capability and energy to provide care. The subscale of self-esteem is scored from 1 to 5 with higher scores suggesting higher levels of self-esteem. The other four subscales are scored on a scale of 1 to 5 with higher scores indicating greater burden. The CRA has demonstrated validity in the caregiver population [25–26]. Scores are aggregated for the four “negative” subscales: effect on schedule, effect on finances, lack of family support, and effect on health. Scores for the negative subscales range from 1 (best) to 5 (worse). Cronbach alpha reliability coefficients have been reported to be above 0.80 for all subscales [25]. In

the current study, Cronbach alphas ranged from 0.67 to 0.83. Cronbach alpha for the subscale of effect on health was 0.67, just below the acceptable threshold of 0.70 [27–28]. This subscale may have had lower reliability because it contains only four items. In addition, one item on this subscale asks the participants to rate the extent to which she agrees or disagrees with the statement: “Since caring for my family member, it seems like I am tired all the time.” Since we recruited caregivers who were providing care for up to 10 yr, this item may not have been meaningful.

Perceived Quality of Life

The Ferran and Powers Quality of Life Index (QLI)–Generic Version III [29] was used to assess perceived QOL. This instrument operationally defines QOL as the degree of satisfaction with domains that are important to oneself and is a global measure of QOL. The tool consists of 33 items that measure satisfaction (1 = very dissatisfied to 6 = very satisfied) and importance (1 = very unimportant to 6 = very important) in four domains: health and functioning, psychosocial/spiritual, social and economic, and family. In addition, an overall global QOL score can be calculated. Scores for each of the four subscales as well as overall QOL range from 0 to 30, with higher scores reflecting higher levels of perceived QOL. The QLI has excellent internal consistency as demonstrated by Cronbach alphas ranging from 0.73 to 0.99 across 48 different studies [29]. In the current study, reliability was excellent at 0.95.

Procedures

The VA Human Subjects Institutional Review Board approved this study and investigators obtained written informed consent from participants. Written questionnaire booklets were mailed to participants with return postage prepaid. Participants were provided with a \$30 retail gift card for study participation.

Analysis

Data were analyzed using SPSS software version 22 (IBM Corporation; Armonk, New York). Missing data occurred at 0 to 3 percent across all variables. To allow for a complete data set for statistical analysis, missing data were replaced using the LISREL 8.8 (Scientific Software International; Skokie, Illinois) [30] multiple imputation procedure (see Schafer [31] for details of the multiple imputation procedure used in LISREL).

Descriptive statistics were used to summarize demographic and key variables. Pearson correlation was used to examine relationships among variables. Variables significantly correlated with QOL were simultaneously entered into linear regression models to identify predictors of QOL. Two-tailed tests were used throughout and significance levels determined at $\alpha \leq 0.05$.

RESULTS

Descriptive Findings

Sample Characteristics

Sample characteristics are reported in **Table 1**. Participants reported a variety of medical problems, with the most frequent problems being low back problems (27.5%) and hypertension (20.0%). The most common type of medication that participants reported taking were antihypertensives (27.5%), followed by acid-reducing agents (22.5%), estrogen derivative or contraceptives (17.5%), and antidepressants (17.5%) (**Table 2**).

Survey Results

All descriptive survey results are reported in **Table 3**.

Table 1.
Demographic characteristics of sample. $N = 40$.

Variable	Value
Age (yr), mean \pm SD	43.1 \pm 15.3
Relationship to Veteran, n (%)	
Married	36 (90.0)
Significant Other	4 (10.0)
Highest Educational Level, n (%)	
No College Degree	17 (42.5)
College Degree or More	23 (57.5)
Race, n (%)	
White	29 (72.5)
Black, Hispanic, Other	11 (27.5)
Household income, n (%)	
<\$75,000	27 (67.5)
\geq \$75,000	13 (32.5)
Employment Status, n (%)	
Employed	22 (55.0)
Not Employed	18 (45.0)
Duration of Caregiving (mo), mean \pm SD	49.4 \pm 27.9
Care Provided per Week (h), mean \pm SD	35.5 \pm 40.4

SD = standard deviation.

Table 2.
Frequency of study participants' medication categories.

Drug Class	Participants (<i>n</i>)	Frequency within Class (%)
Antihypertensives	11	27.5
ACE-I	4	36.4
Beta Blockers	5	45.5
CCB	2	18.2
Acid-Reducing Agents	9	22.5
PPI	5	55.5
H ₂ RA	4	44.4
Estrogens	7	17.5
Estrogen Derivative	2	28.6
OC	5	71.4
Antidepressants	7	17.5
SSRIs	5	71.4
SNRIs	2	28.6

ACE-I = angiotensin converting enzyme inhibitor, Beta Blocker = beta receptor antagonist, CCB = calcium channel blocker, H₂RA = H₂ receptor antagonist, OC = oral contraceptive, PPI = proton pump inhibitor, SNRI = serotonin/norepinephrine reuptake inhibitor, SSRI = selective serotonin reuptake inhibitor.

QLI. The mean score for the QLI was 18.08 ± 5.50 (range: 4.76–28.00 with highest scores suggesting higher QOL). Scores were normally distributed. Mean subscale scores for health and functioning, social and economic, psychological/spiritual, and family ranged from 17.45 to

Table 3.
Means \pm standard deviation (SD) of predictor and outcome variables (*N* = 40).

Variable	Mean \pm SD	Range
Perceived QOL (QLI)	18.08 ± 5.50	4.76–28.00
Health and Functioning	17.45 ± 5.24	4.23–26.77
Psychosocial/Spiritual	17.78 ± 7.12	0.00–30.00
Social and Economic	18.43 ± 6.46	4.75–30.00
Family	19.80 ± 6.60	2.70–29.50
Perceived General Health (SF-12)	2.40 ± 0.74	1.00–4.00
Somatic Symptoms (PHQ-15)	11.38 ± 4.92	1.00–23.00
Caregiver Burden (CRA)		
Self-Esteem	4.08 ± 0.65	2.71–5.00
Disrupted Schedule	3.60 ± 0.90	1.40–5.00
Effect on Finances	3.13 ± 0.95	1.67–5.00
Lack of Family Support	2.70 ± 0.98	1.20–5.00
Effect on Health	2.75 ± 0.75	1.25–4.00

CRA = Caregiver Reaction Assessment, PHQ-15 = Patient Health Questionnaire-15, QLI = Quality of Life Index, QOL = quality of life, SF-12 = 12-Item Short Form Health Survey.

19.80 with the domains of health and functioning receiving the lowest mean score (17.45) and family the highest mean score (19.80), suggesting at least some family support was being provided.

SF-12 General Health. On a scale of 1 (excellent) to 5 (poor), the average rating of general health was 2.40 ± 0.74 with 40.0 percent of participants rating their general health as fair or poor.

PHQ-15. The mean score for the PHQ-15 was 11.38 ± 4.92 (range: 1.00–23.00), indicating moderate to high levels of bothersome somatic symptoms. Over a quarter (27.5%) of participants reported high levels of bothersome somatic symptoms. The most common somatic symptoms reported as “bothering them a lot” were feeling tired or having low energy (57.5%), trouble sleeping (40.0%), and headaches (30.0%). Other symptoms that participants reported as “bothering them a lot” included alterations in bowel functioning (32.5%), nausea or indigestion (27.5%), back pain (27.5%), and joint pain (27.7%).

CRA. The mean score for caregivers on the self-esteem subscale (mean = 4.08 ± 0.65) neared the maximum score of 5.00, suggesting that participants valued their caregiving role. The CRA subscales of disrupted schedule (mean = 3.60 ± 0.90) and finances (mean = 3.13 ± 0.95) were rated the highest of the four negative CRA subscales, suggesting that effect on schedule and finances were considered to be more burdensome than effect on health (mean = 2.75 ± 0.75) and lack of family support (mean = 2.70 ± 0.98).

Predictors of Quality of Life

Bivariate correlations, used to identify variables to include in regression models, indicated that marital status, educational level, race, household income, employment status, relationship to patient, duration of providing care, and number of hours per week of providing care were not associated with QOL. Therefore, using QOL as the dependent variable, the following independent variables were entered into the regression model: perceived health, somatic symptom score, five aspects of caregiver burden (effect on caregiver's self-esteem, schedule, finances, health, and lack of family support), and caregiver age. The model accounted for 64 percent of the variance in the QOL score, $F(8, 31) = 9.59, p < 0.001$. In this model, the caregiver burden subscale scores of self-esteem ($\beta = 0.28, p = 0.02$) and effect on finances

($\beta = -0.27, p = 0.05$) and the somatic symptoms score ($\beta = -0.28, p = 0.04$) had significant partial effects in the model (Table 4).

DISCUSSION

The aims of this study were to describe perceived health, medication use, somatic symptoms, caregiver burden, and perceived QOL and to examine the extent to which these variables are associated with QOL, after accounting for age, in women partners of male Veterans with TBI. Compared with other studies of informal caregivers, participants were younger, but they were similar demographically to other samples of caregivers of Veterans with TBI [17].

Overall, participants reported lower levels of QOL (mean = 18.08 ± 5.50) compared with informal caregivers of patients awaiting lung transplant (mean = 22.81 ± 4.50) [32], caregivers of patients with breast cancer (mean = 22.32 ± 3.40) [33], and caregivers of patients with life-threatening dysrhythmias (mean = 24.20 ± 3.60) [34]. Our finding of moderate levels of QOL is consistent with other studies of QOL in TBI informal caregivers, although direct comparisons are difficult because of the heterogeneity of instruments used to measure study variables. For example, one study of both male and female caregivers of civilians with TBI found that QOL as mea-

sured with the Life Satisfaction Questionnaire was low [35]. Other studies of TBI caregivers using the 36-Item Short Form Health Survey [36] and the World Health Organization Quality of Life- BREF [14,37] also reported low levels of QOL in informal caregivers of individuals with TBI.

Participants rated their overall general health as moderately healthy. However, a large portion (40.0%) reported poor to fair health, which was associated with lack of family support. This finding is consistent with previous studies demonstrating that better health is associated with higher levels of support [38] and lower levels of burden [39]. Most commonly reported health problems included low back pain (27.5%) and hypertension (20.0%). Although reports of physical health problems in female informal caregivers of individuals with TBI are limited, results of a large study ($N = 1,517$) of informal caregivers caring for individuals with cancer demonstrated that low back pain is a common occurrence in spousal caregivers independent of age, sex, education, and income [40]. Increased levels of low back pain in informal caregivers may be associated with the physical aspects of providing care, such as assisting the patient to transfer [41–42]. In addition, previous studies have reported informal caregivers as being at higher risk for coronary heart disease (CHD) and stroke than noncaregivers [43]. Caregivers who are in poor health may be at particular risk of developing CHD [44]. Poor self-care health behaviors [45] and heightened levels of chronic stress associated with inflammation [46] have been attributed to increased CHD risk in informal caregivers. No studies were found that specifically examined low back pain or CHD risk in informal caregivers of Veterans with TBI. Given our findings that low back pain and hypertension were common in our sample, further investigation is warranted.

The most common types of medications used were antihypertensives (27.5% of sample), which is consistent with hypertension being one of the more common health problems reported. The number of participants who reported taking antihypertensives in our study was about 10 percent higher than that of the general U.S. population [47], which could be attributed to differences in age, comorbidities, etc. Acid-reducing agents (22.5% of sample) were the second most common medication reported by participants.

Over a fourth of our sample reported high levels of somatic symptoms, with fatigue and difficulties sleeping

Table 4.
Variables associated with quality accounting for age ($N = 40$).

Variable	$b \pm SE$	β	p -Value
Age	0.05 ± 0.04	0.14	0.25
Perceived General Health	-1.47 ± 0.84	-0.20	0.09
Somatic Symptoms	-0.32 ± 0.15	-0.28	0.04*
Caregiver Burden			
Self-Esteem	2.36 ± 0.91	0.28	0.02*
Disrupted Schedule	-0.86 ± 0.91	-0.14	0.35
Effect on Finances	-1.64 ± 0.75	-0.27	0.05*
Lack of Family Support	-1.19 ± 0.82	-0.21	0.16
Effect on Health	-0.03 ± 1.08	-0.01	0.98

Note: Adjusted $R^2 = 0.64, F(8,31) = 9.59, p < 0.001$.

*Statistically significant.

SE = standard error.

being reported in almost half of our participants. Low back pain was reported by over a quarter of the sample, consistent with this being a frequently reported medical problem. Our findings are consistent with those of Kreutzer et al., who also found that nearly a quarter of their sample of informal caregivers of civilians with TBI reported somatic symptoms [13]. Although no studies were found that specifically examined fatigue and sleep in informal caregivers of individuals with TBI, other studies of caregivers of cancer patients have reported high levels of fatigue and sleep disturbances in caregivers [48–49]. Given the importance of sleep to informal caregivers to not only their overall well-being but potentially their ability to care for the patient, more studies are needed. This is particularly important because sleep disturbance could be due to difficulty going to sleep or staying asleep, both of which can be directly addressed with currently available treatments, but the origin of the sleep disruption should be further specified in future research.

Scores for the caregiver burden subscales in our sample were somewhat different than those found in other studies of informal caregivers for other conditions but consistent with other caregiver studies of Veterans with TBI. Participants in our study reported greater disruption to their daily schedule than informal caregivers of patients with advanced cancer [50] or stroke [51]. Furthermore, our participants reported higher levels of financial problems as a result of caring than other informal caregivers [50–52]. These results may be attributed to caregivers in our sample being younger and having less life experience than informal caregivers in other studies [50–51,53] or, as suggested in other studies, a result of exhausting personal savings, reductions in income from reducing or terminating paid working hours in order to provide care [54], or Veteran's impulsive spending habits that can affect family finances. Mean subscale scores for caregiver self-esteem were similar to scores of spousal caregivers of patients 3 yr after stroke [51] and caregivers of lung transplant candidates [32]. Self-esteem scores have also been shown to be lower among spouses than parents caring for a Veteran with TBI [55]. High self-esteem scores in our study may reflect the participants' high value of caring for the Veteran. Family support and effect on health subscale scores in our study were similar to those of other studies of informal caregivers [50–51].

An important contribution of this study is the examination of perceived health, somatic symptoms, and caregiver burden on caregiver QOL. Although perceived

health was not significantly associated with QOL, higher levels of somatic symptoms were associated with lower levels of QOL. Considering fatigue and sleep disturbance were the most commonly reported somatic symptoms, interventions targeting these symptoms may be valuable in improving overall QOL. Effect on finances also explained unique variance in QOL in our model, with greater financial burden predicting worse QOL. This finding is consistent with those of a study examining caregiver burden and QOL in informal caregivers of lung transplant candidates [32]. Although more research is needed, financial burden, particularly in younger informal caregivers who may be faced with decreasing their work hours in order to care for their loved one, may be an important consideration in caring for families of Veterans with TBI.

Importantly, higher levels of caregiver self-esteem predicted higher levels of QOL in our model. This finding suggests that acknowledging and supporting the important role that informal caregivers play may be critical to their overall well-being and, ultimately, their ability to effectively care for the Veteran. In a study of spouses caring for a stroke survivor, positive aspects of caregiving buffered the negative experience of caregiving [51]. Although our sample size was not powered to assess self-esteem as a mediator between caregiver burden and QOL, this may be an important process to examine in future studies.

LIMITATIONS

Limitations of this study include the cross-sectional design, small sample size, and convenience sampling. Because of these factors, the findings are not generalizable. In addition, individuals who chose not to participate in our study may have differed from participants. Furthermore, we did not measure the severity of the TBI. Future research may benefit from estimating severity at time of TBI using data from the medical record and self-report data from the Veteran and describing the relationship of severity of TBI with functional and caregiving needs of the individuals with TBI. Furthermore, longitudinal research examining how caregiver burden, health, and QOL may change over time may contribute to the development of interventions tailored to meeting the specific needs of the caregiver over the caregiving trajectory.

CONCLUSIONS

In summary, this is the first study to examine the associations among perceived health, somatic symptoms, and caregiver burden and QOL in female partners caring for Veterans with TBI. Overall, participants in our study reported moderately low QOL. Findings suggest that more severe somatic symptoms and greater financial problems negatively affect QOL while higher levels of self-esteem positively affect QOL. More research is needed to inform the development of interventions and policies to support family-centered care for Veterans with TBI.

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