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Group Differences Among Caregivers of Civilians and Service Members or Veterans with Traumatic Brain Injury

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Abstract

Objective: To examine group differences among caregivers of service members/veterans (SMVs) and civilians with traumatic brain injury (TBI).

Design: An observational research study examining the group differences between caregivers of SMVs and civilians with TBI. The data presented was collected as part of a larger study that calibrated and validated the TBI-CareQOL item banks.

Setting: Participants in this multicenter study completed an online survey via a study-specific website. Surveys were completed at the study site, at home or via phone interview. Civilian caregivers were recruited from four rehabilitation hospitals and caregivers of SMVs were recruited through community outreach and collaboration with the Hearts of Valor.

Participants: Participants consisted of 344 caregivers of civilians with TBI and 129 caregivers of SMVs with TBI.

Interventions: Not applicable.

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Main Outcome Measures: Zarit Burden Interview Scale, TBI-CareQOL, and Mayo Portland Adaptability Inventory, 4th revision (MPAI-4)

Results: Of the independent variables included in the logistic regression model that classified military-affiliated versus civilian caregivers five were statistically significant: age, spousal status, time since injury, MPAI-4 Adjustment, and TBI-CareQOL Feeling Trapped.

Conclusions: The results indicate that caregivers of SMVs were more likely to report worse emotional and social adjustment among the individuals with TBI and caregivers of SMVs were more likely to report greater levels of feeling trapped by their caregiving duties.

Keywords

Traumatic brain injury; caregivers; military; veterans

Moderate to severe traumatic brain injury (TBI) is a serious public health concern that can lead to long-term disability and requires substantial resources for rehabilitation. Epidemiological studies of civilians with TBI estimate that each year 1.1 million Americans are treated for TBI in emergency departments and about 3.2 million are living with disability following TBI.¹ Among military personnel, TBI is a common injury among those returning from combat operations and among those injured through training and other means.^{2,3} Since 2000, over 350,000 active duty service members were diagnosed with a TBI.⁴ In addition, service members are likely to experience repeated injuries, other bodily injuries, and psychological comorbidities with the TBI.⁵⁻⁸ Often, individuals with TBI are treated in the acute and subacute phases of their injury at rehabilitation hospitals and clinics. As individuals with TBI are transferred out of services, the burden of care generally shifts onto the families of the injured.⁹

Many caregivers of individuals with TBI report a high burden of care and decreases in health-related quality of life. Among civilian caregivers, these include lower satisfaction with life and increased psychological distress.¹⁰⁻¹³ Among caregivers of individuals with military-related TBI these include negative impact to caregivers' social health including finances, isolation, and disrupted social roles, as well as worse emotional health including feelings of loss, anger, depression, and anxiety.^{9,14,15} As recognition grows that caregiving for individuals with TBI can have a negative impact on well-being, civilian and military institutions are seeking to improve provision of care for this underserved population.⁸

Literature on TBI points to some important differences between caregivers of service members or veterans (SMVs) and civilians. For instance, caregivers of SMVs with TBI have reported that in addition to providing assistance with activities of daily living (ADL), caregiving duties largely consist of managing emotional issues as well as navigating legal, military, and medical systems.^{9,10,14,15} In a series of focus groups, military caregivers reported experiencing hypervigilance around the individual with TBI to avoid upsetting the service member, a theme that was less robust in civilian caregivers.^{10,14} Carlozzi et al. 2016,¹⁴ postulated this may be related to high rates of comorbid posttraumatic stress disorder among the service members with TBI. In addition, caregivers of SMVs reported high rates of anger towards the military or VA healthcare system which was related to fear

regarding potential loss of compensation for caregiving duties and barriers to availability and accessibility of the healthcare system. Anger regarding barriers to healthcare access was verbalized less commonly by civilian caregivers.¹⁰ Although no direct comparisons have been made, the existing literature suggests that caregivers of service members or veterans (SMVs) with TBI may experience greater caregiver burden and distress due to problems associated with SMVs' emotional health and navigating the VA healthcare system.

The purpose of the current study was to fill a gap in the literature by examining differences among two non-equivalent groups of caregivers. First, the study examined group differences regarding demographics and injury characteristics. Second, the study examined which caregiver outcomes best distinguished the caregivers of SMVs with TBI from the caregivers of civilians with TBI. We hypothesized that after controlling for demographic and injury differences, caregivers of SMVs would report worse caregiver outcomes and worse emotional adjustment among the SMVs with TBI. Although the data are limited by important differences in our samples, this study is a first attempt to highlight what may be important distinctions between caregivers of civilians and SMVs with TBI.

METHODS

Caregiver Participants

Participants for this study were recruited as part of a larger study aimed at assessing health-related quality of life in caregivers of persons with TBI.¹⁶ With regard to the proposed analysis, we examined responses from caregivers of SMVs and civilians with TBI. Caregivers of SMVs with TBI were recruited through community outreach efforts lead by [redacted for review]. This involved local [redacted for review] and national community outreach efforts that were done in collaboration with Hearts of Valor- an organization that serves SMVs and their families. As a part of these community-based efforts, staff from [redacted for review] traveled to locations with active Hearts of Valor support groups (San Diego, CA, Orlando, FL, Columbus, GA, Clarksville, TN, San Antonio TX) and engaged caregivers that were interested in study participation. A total of 129 caregivers of SMVs were enrolled through these combined community –based efforts. Caregivers of civilians with TBI (N=344) were recruited from three TBI model system centers ([redacted for review]), as well as the [redacted for review]. These caregivers were identified using existing TBI caregiver databases, medical record searches, and community outreach. All caregivers had to be at least 18 years old, had to be able to read and understand English, and be caring for an individual with a documented TBI that was sustained after age 18. The person with the TBI had to be 1 year post-injury. A caregiver was defined as someone that provides physical assistance, financial assistance, or emotional support to an individual with a TBI. In addition, caregivers of SMVs were required to endorse a minimal level of support based on the following questions, “On a scale of 0–10, where 0 is “no assistance” and 10 is “assistance with all activities,” how much assistance does the person you care for require from you to complete activities of daily living due to problems resulting from his/her TBI? Activities could consist of personal hygiene, dressing and undressing, housework, taking medications, managing money, running errands, shopping for groceries or clothing, transportation, meal preparation and cleanup, remembering things, etc.” Caregivers of SMVs

that indicated a response of 1 were considered eligible. Professional caregivers were not eligible for this study, but family members who received compensation for their caregiving duties were included. Characteristics of each group and group differences are discussed in greater detail in the Results section below.

Inclusion criteria for TBI severity was different for the SMVs and civilian samples. Among the military sample, caregivers were required to be providing care to an individual with a TBI of any severity that was documented by either a Department of Defense or Veteran's Affairs treatment facility. This includes any diagnosis of TBI in the medical records regardless of severity. Among the civilian sample, caregivers were required to be providing assistance to an individual with a medically documented complicated mild, moderate, or severe TBI according to TBI Model System criteria.¹⁷ Specifically, the person had to have an injury caused by an external mechanical force as evidenced by at least one of the following: 1) post traumatic amnesia >24 hours, 2) trauma related intracranial neuroimaging abnormalities, 3) loss of consciousness greater than 30 minutes not due to sedation or intoxication, or 4) Glasgow Coma Scale (GCS) in the emergency room of less than 13, not due to intubation, sedation or intoxication.

Measures

Caregivers completed several self-report measures during the course of the study visit including a demographics questionnaire, the Mayo Portland Adaptability Inventory 4th edition (MPAI-4),^{18,19} the Zarit Burden Inventory Scale,^{20,21} and 4 item banks from the TBI-CareQOL.^{16,22} In addition, caregivers completed questions regarding age, gender, race/ethnicity, educational attainment, relationship to the person with TBI, age of the person with TBI, how the person with TBI was injured, time since injury, perceived injury severity, and how long the caregiver had been providing care, among others.

Mayo Portland Adaptability Inventory, 4th revision (MPAI-4).^{18,19} The MPAI-4 is a 35-item proxy-report measure designed to assess functional ability for individuals with TBI. Its items result in three domain areas including ability (i.e., sensory, motor, and cognitive), adjustment (emotional, behavioral, awareness, and social adjustment), and participation (community engagement, leisure activities, self-care, initiation, employment, and financial management). Items are rated on a 0–5 scale and converted into T-scores with higher scores indicating greater impairment.

Zarit Burden Interview.^{20,21,23} The Zarit Burden Interview (ZBI) consists of 22 items regarding the emotional, social, and financial problems that result from adopting a caregiving role. The measure was developed for all caregiver types. Items are summed to create a total burden raw score with higher scores indicating greater burden. This measure was used in conjunction with the TBI-CareQOL measures which identify specific aspects of burden relevant to TBI.

TBI-CareQOL.^{16,22} New TBI caregiver-specific item banks were administered using computerized adaptive testing (CAT) and short forms. These items included Feeling Trapped²⁴ (restricted by caregiving duties), Feelings of Grief/Loss²⁵ (loss related to the caregiver themselves, as well as the person with TBI), Caregiver-Specific Anxiety²⁶ (anxiety

related to the caregiver role including re-injury concerns, worry about leaving the person alone), and Caregiver Strain²⁷ (burden, stress, feeling overwhelmed). Only responses from the short form versions were used in this study. Higher scores indicate more of the trait being measured.

Procedures

Participants completed the surveys in-person, by phone interview, or online via a study-specific website via the Assessment Center platform (www.assessmentcenter.net) as part of a larger study that calibrated and validated the TBI-CareQOL item banks.¹⁶ Site personnel registered the participant for the study and then provided the participant with a URL and unique pin and password to access this site. Participants were compensated \$50 for their involvement in this study. Data were collected in accordance with local institutional review boards at each site, and participants provided informed consent prior to participation or secured a waiver for documentation of informed consent.

Data Analyses—Descriptive data regarding demographics and injury characteristics are provided and group differences were presented using chi-square and t-tests as appropriate. A binary logistic regression model was used to assess which demographic, injury, and caregiver outcome variables predicted group membership (i.e., military-affiliated or not military-affiliated). Injury severity was not included in the model because only caregiver report of injury severity was available for both groups, which may not be a reliable indicator of true severity. Linearity was established between the independent and dependent variables. There was no indication of multicollinearity, as evidenced by $VIF < 10$. The data were checked for outliers and no data points were deemed necessary to remove. Cases with missing data were not included in the analyses (<8% missing data).

RESULTS

Caregiver demographics are presented in Table 1. The caregivers of SMVs with TBI were younger in age than civilian caregivers ($t(377.1)=15.2, p<.001$) and had a greater level of education than the caregivers of civilians (Pearson $\chi^2=26.4, p<.001$). There was no significant group difference regarding the average time spent caring for the individual with TBI ($t(459.1)=.8, p=.399$). A greater number of caregivers of SMVs with TBI had health care power of attorney compared to civilian caregivers (Pearson $\chi^2=11.2, p=.004$).

Demographics of the individuals with TBI are presented in Table 2. The SMVs with TBI were significantly younger than the civilians with TBI ($t(437.5)=6.1, p<.001$). Time since injury also differed between groups such that SMVs had more remote injuries as compared to civilians (Pearson $\chi^2=16.54, p<.001$). In addition, perceived injury severity was recorded based on caregiver reports. Caregivers were asked to respond to the question, “At the time of the injury, how severe was this person’s traumatic brain injury?” Response choices were: mild, moderate, severe, or unsure/don’t know. Caregivers of SMVs reported caring for individuals with less severe injuries than caregivers of civilians (Pearson $\chi^2=198.95, p<.001$). That said, goodness of fit analyses using GCS scores that were only available for the civilian sample indicated caregiver reports were not reliable measures of true injury severity (Kappa = .10, $p=.002$). For instance, while 66.0% of civilian caregivers correctly identified

the severity of the injury, 29.4% overestimated the injury severity and 4.6% underestimated the injury severity.

A logistic regression analysis was used to examine the differences between caregivers of SMVs versus civilians. The final model correctly classified 95.6% of civilian caregivers and 88.3% of caregivers of SMVs (Cox & Snell $R^2=.54$). Of the independent variables included in the model only five were statistically significant: age, spousal status, time since injury, MPAI-4 Adjustment, and TBI-CareQOL Feeling Trapped (Table 3). Being younger in age and being the spouse of the person with TBI were associated with higher odds of being a caregiver of an SMV. In addition, longer time since injury was significantly associated with being a caregiver of an SMV. With regard to post-injury functioning, when all other independent variables were held constant, having high scores on the MPAI-4 Adjustment scale was associated with higher odds of being a caregiver of an SMV. For each unit increase on the MPAI-4 Adjustment scale there was a 27% increase in the odds of being the caregiver of an SMV. With regard to caregiver outcomes, when all other independent variables were held constant, feeling trapped by caregiver duties was associated with higher odds of being a caregiver of an SMV. For each unit increase on the TBI-CareQOL Feeling Trapped scale there was an 11% increase in the odds of being a caregiver of an SMV.

DISCUSSION

This study examined differences between two non-equivalent groups of caregivers of individuals with TBI. Caregivers of SMVs were younger in age, were more likely to be the spouse of the individual with TBI than caregivers of civilians, and were caring for SMVs that had more remote injuries (i.e. longer time since injury). Caregivers of SMVs were also more likely to report that the SMVs with TBI had worse emotional adjustment and were more likely to report feeling trapped by their caregiving duties than caregivers of civilians with TBIs.

That caregivers of SMVs reported worse emotional adjustment among the individual with TBI than civilian caregivers, warrants attention. Prior research has demonstrated that caregivers of SMVs with TBI report managing emotional problems as a central responsibility of their caregiving duties even in the absence of significant cognitive or motor impairments.⁹ Given the high rates of post-traumatic stress disorder (PTSD) and difficulties with reintegrating into civilian life among veterans it is likely that SMVs with TBI have emotional adjustment issues that are specific to serving in the military.²⁸ In addition, research on SMVs without TBI has implicated the presence of PTSD and other mental health symptoms as a primary cause of worse caregiver outcomes, particularly among spouse caregivers.^{29–31} These findings in the context of previous research point to SMVs having worse emotional adjustment that likely impact caregiver responsibilities and caregiver emotional well-being.^{10,14} The findings from this study support the need for more broad-based treatment for those with TBI who are SMVs. This treatment may need to incorporate support for the transition from the military into the community and PTSD intervention, as direct treatment of these issues in the person with TBI will likely result in better emotional adjustment and functioning, which subsequently improves caregiver emotional adjustment and decreased burden. As such, caregivers of SMVs of TBI may

require greater support from their service providers on how to cope with the emotional problems of the individual they care for that may or may not be associated with the TBI itself.

Feeling trapped by caregiving duties was associated with greater likelihood of being a caregiver of an SMV with TBI. Although the current study did not investigate causal factors, some possible explanations might include that these caregivers are primarily the spouse of the SMVs, are younger in age and have higher education level. It is reasonable to suspect that such caregivers may have needs for social and professional participation that are difficult to accomplish while caregiving. In addition, research has indicated that caregivers of SMVs report that they manage emotional issues^{9,10,14,15} and caregiving in the context of emotional adjustment problems, such as PTSD or social withdrawal, may have a distinct emotional impact on the caregiver. The relationship between worse emotional adjustment among the individual with TBI and feeling trapped by caregiver duties among caregivers of SMVs should be examined in future research and may be important for development of caregiver interventions.

The demographic differences among caregivers and differences among the injury characteristics warrant comment. The caregivers of SMVs were more likely to be the spouse of the individual with TBI and be younger in age. These findings are consistent with trends reported in a recent RAND report, which found that caregivers of post-9/11 veterans differed from civilian caregivers across a number of characteristics including age and relationship to the caregeeve.³² Consistent with the conclusions from the RAND report, the findings from this study indicate that military-affiliated caregivers, particularly of post-9/11 SMVs, represent a distinct group of caregivers from civilians that may require tailored services.

Study Limitations

There are several important limitations to the study. For one, the military and civilian caregivers were recruited through different mechanisms. The civilian cohort was recruited from admission to a model system facility. The military-affiliated cohort was recruited through Hearts of Valor which is an organization designed to support caregivers. It is reasonable to assume that family members who take the initiative to register with Hearts of Valor may do so because they are experiencing caregiver stress. It is reasonable to assume that these caregivers, who self-select to Hearts of Valor, are a more-stressed subset of all military caregivers creating a selection bias. In addition, while medical confirmation of TBI severity was required for caregivers of civilians, documentation for TBI severity was lacking for the caregivers of SMVs. While the majority of caregivers of civilians were caring for an individual with severe injuries, we would expect that the majority of caregivers of SMVs were caring for an individual with a mild injury given that these participants were recruited from community-based outreach. This discrepancy introduces a potentially confounding variable. For example, there may be differences in caregiver training depending on injury severity and or institutions that provide TBI services. The course of treatment for civilians included inpatient services but it is unknown whether service members also had inpatient services. If combat-wounded service members have a delay in treatment, or do not receive

any inpatient services, this could result in differences in exposure to caregiver training and affect caregiver burden outcomes.

There are also important demographic differences; military caregivers were younger in age, were more likely to be the spouse of the individual with TBI, and had higher levels of education. It is possible that these demographic differences are specific to this sample and are not reflected among caregivers of SMVs at large. Future research that compares demographically similar military affiliated and civilian caregiver groups would be important to further investigate this important topic. Race/ethnicity is another variable that may be impacting caregiver perceptions of burden, as has been noted in some prior research.³³

Another important limitation is that there are no data regarding TBI individuals' comorbid medical and mental health conditions. As such, the individuals with TBI may be suffering consequences from other injuries or health conditions not described in this study that could contribute to burden of care. It should also be noted that functional abilities reported in this study are subjective accounts from the caregiver and therefore are subject to biases in appraisal. Finally, this a cross-sectional study which limits the long-term prediction of these factors with regard to caregiver outcomes.

Conclusion

This is the first study to point to important differences between caregivers of SMVs with TBI and caregivers of civilians with TBI. Results indicated that caregivers of SMVs in this sample were younger in age, and had a spousal relationship to the person with TBI. When demographic differences were statistically controlled for, caregivers of SMVs were more likely to report worse emotional adjustment among the SMV with TBI and feeling trapped by their caregiver duties. These findings suggest that caregivers of SMVs with TBI have different characteristics and are likely coping with different presentations than civilian caregivers of individuals with TBI.

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ABBREVIATIONS

ADL	Activities of daily living
GCS	Glasgow coma scale
MPAI-4	Mayo Portland Adaptability Inventory, 4 th revision

SMVs	Service members or veterans
TBI	Traumatic brain injury

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Table 1

Caregiver demographics

Variable	Civilian Caregivers (N=344)	Military Caregivers (N=129)
Age, mean (SD)	51.6 (14.0)	35.6 (8.5)
Female, n (%)	267 (77.6)	129 (100)
Race, n (%)		
White	247 (71.8)	106 (82.2)
Black/African American	70 (20.3)	6 (4.7)
Other	27 (7.8)	17 (13.2)
Missing	1 (.3)	
Highest Education, n (%)		
Less than 12 years	27 (7.8)	2 (1.6)
High-school/GED	66 (19.2)	6 (4.7)
Some college	90 (26.2)	47 (36.4)
College or post-graduate degree	160 (46.5)	74 (57.4)
Missing	1 (.3)	0
Household income, n (%)		
Less than \$20,000	72 (20.9)	10 (7.7)
\$20,000-\$39,999	56 (16.3)	29 (22.5)
\$40,000-\$74,999	86 (25.0)	51 (39.5)
More than \$75,000	114 (33.1)	36 (27.9)
Do not know	13 (3.8)	3 (2.3)
Missing	3 (.9)	0
Relationship to patient, n (%)		
Spouse/Partner	126 (36.6)	124 (96.1)
Parent	123 (35.8)	5 (3.9)
Child	24 (7.0)	0
Other family member	42 (12.2)	0
Other	29 (8.4)	0
Years of care, mean (SD)	5.9 (6.5)	5.5 (2.8)
Health care power of attorney, n (%)	106 (30.8)	62 (48.1)

Note: n = sample size, GED = General Education Diploma, SD = standard deviation

Table 2

Demographics and injury characteristics for persons with TBI

Variable	Civilians (N=344)	Military (N=129)
Gender (Male), n (%)	257 (74.7)	129 (100)
Age, M (SD)	42.3 (14.6)	36.1 (7.2)
Time since injury, n (%)		
Less than 18 months	31 (9.0)	5 (3.9)
18 months to 3 years	72 (20.9)	11 (8.5)
Greater than 3 years	229 (66.6)	112 (86.8)
Missing	12 (3.5)	1 (.8)
Mechanism of injury, n (%)		
Motor vehicle accident	184 (53.5)	6 (4.7)
Fall	55 (16.0)	7 (5.4)
Gunshot wound	23 (6.7)	1 (.8)
Pedestrian struck by vehicle	25 (7.3)	0
Assault	29 (8.4)	3 (2.3)
Struck by object/fragment	4 (1.2)	2 (1.6)
Thrown against object	0	1 (.8)
Blast injury	0	95 (73.6)
Not sure/do not know	2 (.6)	
Other/Multiple modes	6 (1.7)	13 (10.1)
Missing	1 (.3)	0
Perceived injury severity, n (%)		
Mild	8 (2.3)	41 (31.8)
Moderate	27 (7.8)	43 (33.3)
Severe	282 (82.0)	19 (14.7)
Don't Know/Not Sure	25 (7.3)	24 (18.6)
Missing	2 (.5)	2 (1.6)

Note: n = sample size, SD = standard deviation

Table 3

Predictors of Military Affiliation

Variable	B	SE	Wald	df	p	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Age	-.10	.02	25.37	1	<.001	.91	.87	.94
Gender	-19.70	3653.40	<.001	1	.996	<.001	<.001	.
Education level	.05	.06	.71	1	.400	1.05	.94	1.18
Spouse of person with TBI	-2.85	.57	24.65	1	<.001	.06	.02	.18
Time since injury	1.16	.38	9.26	1	.002	3.17	1.51	6.68
MPAI-4 Ability	-.03	.04	.74	1	.388	.97	.90	1.04
MPAI-4 Adjustment	.24	.05	23.41	1	<.001	1.27	1.15	1.39
MPAI-4 Participation	-.06	.03	3.31	1	.069	.94	.89	1.00
TBI CareQOL Feeling trapped	.10	.04	6.78	1	.009	1.11	1.03	1.20
TBI-CareQOL Grief/Loss	-.01	.05	.02	1	.895	.99	.90	1.09
TBI-CareQOL Worry	-.05	.04	1.39	1	.239	.95	.88	1.03
TBI-CareQOL Strain	<.01	.04	.01	1	.940	1.00	.92	1.09
Zarit Burden Inventory	-.02	.03	.38	1	.538	.99	.94	1.03