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## Caring for our wounded warriors: A qualitative examination of health-related quality of life in caregivers of individuals with military-related traumatic brain injury

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## Abstract

**Objective**—To develop a conceptual framework that captures aspects of health-related quality of life (HRQOL) for caregivers of individuals with military-related traumatic brain injury (TBI).

**Design**—Qualitative data from nine focus groups composed of caregivers of wounded warriors with a medically documented TBI were analyzed.

**Setting**—Focus group participants were recruited through Walter Reed National Military Medical Center (WRNMMC), community outreach and support groups.

**Participants**—45 caregivers of wounded warriors who had sustained a mild, moderate, severe, or penetrating TBI.

**Results**—Qualitative frequency analysis indicated that caregivers most frequently discussed social health (44% of comments), followed by emotional (40%) and physical health (12%). Areas of discussion that were specific to this population included: anger regarding barriers to health services (for caregivers and service members), emotional suppression (putting on a brave face for others, even when things are not going well), and hypervigilance (controlling one's behavior/environment to prevent upsetting the service member).

**Conclusion**—Caring for wounded warriors with TBI is a complex experience that positively and negatively affects HRQOL. While some aspects of HRQOL can be evaluated with existing measures, evaluation of other important components does not exist. The development of military-specific measures would help facilitate better care for these individuals.

## Keywords

Caregiver; Health-Related Quality of Life; Outcome Assessment (Health Care); Quality of Life; Service Members; Traumatic Brain Injury; Underserved Populations; Veterans; Wounded Warriors

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Caregivers of individuals with military-related traumatic brain injury (TBI) are an underserved population.<sup>1</sup> TBI is a common injury among military service members, including those returning from combat operations (e.g., Operations Iraqi Freedom and Enduring Freedom), and those injured through training, accidents and other means.<sup>2,3</sup> From 2000 through 2015, over 325,000 service members were diagnosed with TBI (1.5% penetrating injuries, 1.0% severe, 8.5% moderate, 82.4% mild and 6.6% unclassifiable).<sup>4</sup> A better understanding is needed to determine how family members' health-related quality of

life (HRQOL) is affected by having to provide care for a service member who sustains a TBI. HRQOL represents a multidimensional construct reflecting the impact of a disease, disability, or its treatment, on mental, physical, and social well-being.<sup>5</sup> This can be contrasted with the more general term of “quality of life” which also encompasses general well-being,<sup>6,7</sup> but lacks a consensus definition.

The limited research examining caregivers of service members with TBI, suggests that these caregivers experience less family cohesion and nurturance, greater emotional distress and mental health problems, and increased financial strain than their civilian counterparts.<sup>8-13</sup> These difficulties are in addition to the burdens related to deployment and reintegration (e.g., high divorce rates and family disruption).<sup>14-16</sup> Service members with TBI are also more likely than civilians with TBI to experience repeat injuries, as well as comorbid physical and psychological ailments simultaneous with the TBI (i.e., polytrauma).<sup>14,15</sup> Polytrauma occurs when an individual experiences concurrent injuries to multiple body parts and organ systems; this can include major extremity trauma (single or multiple amputations), musculoskeletal injuries, burns, spinal cord injury, auditory and visual impairment and facial disfigurement. These injuries can result in chronic pain, sexual dysfunction, substance misuse or other problems in addition to combat-related mental health problems (e.g., posttraumatic stress disorder), all of which may make long-term caregiving more complicated.<sup>17-27</sup>

In order to address this underserved population, Congress mandated the development of a family caregiver curriculum to improve educational support and to increase attention to the respite needs of caregivers of patients with TBI.<sup>28</sup> This curriculum, The Traumatic Brain Injury Guide for Caregivers of Service Members and Veterans, was intended for family caregivers of service members and veterans who have sustained a moderate or severe TBI. It is commonly provided to family caregivers by case managers and clinicians from the Department of Defense (DoD) and Veterans Affairs (VA).

In addition to the Caregiver Curriculum, the United Health Foundation funded the 2010 Caregiver of Veterans Report.<sup>27</sup> This report identified caregivers of wounded service members (regardless of injury etiology) as often experiencing marital strain, decreased time for themselves, and experiencing feelings of isolation. Relative to their civilian caregiver counterparts, caregivers of wounded service members reported remaining in the caregiver role for a longer period of time and having greater physical strain, as well as higher levels of emotional stress, inability to work, and financial burden.

Furthermore, in 2006 Congress mandated that family members of a service member incurring TBI” be one of the primary focuses of DoD research efforts for service members of Operations Iraqi Freedom and Enduring Freedom (section 721 of the John Warner National Defense Authorization Act for Fiscal Year 2007). This mandate resulted in a 15-year longitudinal study examining the long-term effects of TBI on both the surviving service members and his/her family system. Authors of this manuscript (TAB, LMF, RTL) are currently leading several research projects addressing this mandate.

Taken together, although many of our wounded warriors receive high quality medical care for service related injuries, the caregivers and families of these individuals often do not receive the same level of attention. Therefore, the purpose of the current study is to identify and characterize salient domains of HRQOL that are important to caregivers of service members with military-related TBI. This work should help identify the most appropriate areas for clinical interventions targeted at improving the lives of both the caregiver and service member/veteran with TBI. Furthermore, this analysis will serve as the foundation for the development of a new measurement system designed to capture the most salient aspects of HRQOL for these caregivers. This measurement system can be used to sensitively examine the interrelationships among caregiver and care-recipient HRQOL, and serve as an endpoint for clinical trials targeted at improving the lives of these service members and their families.

## Methods

### Participants

Focus groups were conducted with caregivers of individuals with military-related TBI (mild, moderate, severe, and penetrating) in order to identify the most important and relevant HRQOL domains for TBI caregivers. Nine focus groups were conducted that included a total of 45 unique caregivers of service members and veterans recruited through hospital-based and nationwide community outreach procedures at Walter Reed National Military Medical Center (WRNMMC; Bethesda, MD), the University of Michigan (Ann Arbor, MI), and in conjunction with Hearts of Valor—a community organization designed to support caregivers of wounded warriors (medical documentation is required to join this organization; TN and WA). Inclusion criteria were that caregivers be at least 18 years old, be able to read and understand English, and be caring for an individual with a medically documented mild, moderate, or severe and/or penetrating TBI (the individual with the TBI was required to be 1 year post injury and meet DoD criteria for a mild, moderate, severe or penetrating TBI; Table 1).<sup>29</sup> Medical record documentation was required to support the TBI diagnosis. Caregivers could be providing care for someone with or without comorbid bodily injuries. The caregiver role was confirmed using the following question, “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 indicating responses of 1 were eligible for participation in this study. Data were collected in accordance with local institutional review boards; informed consent was provided by participants prior to participation.

Table 2 provides demographic data for study participants. Caregivers were typically in their 30's (average age = 37.3 years; SD = 9.6), primarily female (93%) and Caucasian (84%); 9% were Hispanic/Latino. On average, caregivers reported serving in their caregiver role for 4.4 years (SD=2.5, range 0.6 – 10). With regard to relationship to the service member, the majority of caregivers were spouses (73%), followed by children (16%), other relationships

(male partner, fiancé, brother; 7%), and parents (4%). Service members were 34.6 years of age on average ( $SD=6.4$ ); 67% served in the U.S. Army, 11% Marine Corps, 7% Army National Guard, 4% Air Force, 4% Army Reserves, 4% Navy, or 2% Navy Reserves. In addition, 9% of the service members were active duty (medical board pending; missing for 5 people). With regard to TBI severity, 49% were mild injuries, 13% moderate, 7% severe, and 11% were penetrating injuries (this data is unavailable for 20% of our participants). Sixty-seven percent of the TBIs were blast-related injuries (i.e., primary, secondary, and tertiary blast), and 33% were not blast-related. Forty-two percent of the injuries occurred as a part of a motor vehicle accident, 16% were gunshot wounds, 13% were thrown against an object, 7% were falls, 7% were struck by an object, 9% indicated more than one injury, and 2% reported other sources of injury (e.g., improvised explosive device, rocket fire). The majority of service member TBIs were sustained during combat deployment (69% were combat-related, and 13% were non-combat related). Of the remaining, 13% were not deployed at the time of injury, and 4% selected more than one option (indicative of multiple TBIs).

### Data Collection and Analysis

Focus groups were about 90 minutes in length and led by one to two female moderators with extensive experience conducting focus groups (at least one co-moderator was always a PhD-level clinical psychologist; NEC or ALK). Moderators utilized broad, open-ended questions to allow participants to articulate how being a caregiver has affected their overall HRQOL (see Appendix 1 for the Focus Group Interview Guide). Follow-up prompts included open-ended questions designed to solicit what aspects of life had been most affected, and prompts to discuss social, emotional, physical, and cognitive health. Focus groups were audio-recorded, transcribed verbatim, and de-identified. Frequency analysis<sup>30-32</sup> was employed according to established methodology using NVIVO 10 software.<sup>33-36</sup> This methodology<sup>35</sup> utilizes the development of a domain framework (conceptual model), open and axial coding, selective coding, and descriptive analysis. Three project team members (NEC, ALK, and TAB) collaboratively identified major content areas and a list of subdomains through transcript review (open coding) and reconciled these content domains with the codebooks that were used to analyze the civilian-caregiver data.<sup>37</sup> This information was then used to develop a hierarchical taxonomy for each major content area. The 12 members of the investigator team (9 with PhD's, 2 with master's degrees, and one with a bachelor's degree) with expertise in caregivers of civilians with TBI, caregivers of individuals with military TBI, patient-reported outcome measurement development, civilian TBI, and military TBI, reviewed and modified the codebooks using an iterative process. This resulted in separate codebooks for four major content areas: mental health, physical health, social health, and military-related services. Each transcript was analyzed separately, according to each codebook. Thus, the same text could be coded multiple times, according to the different codebooks. Prior to coding, raters (bachelor's or master's level assistants who were supervised by a PhD-level psychologist) were required to establish inter-rater reliability (i.e., 80% agreement). Once inter-rater reliability was established, two coders coded each transcript independently; the two raters were required to establish consensus on any discrepancies that were identified during the coding review process.

## Results

Saturation (i.e., the point at which no new information was obtained), was achieved by the eighth focus group. In accordance with established qualitative methodology,<sup>35</sup> an additional focus groups was conducted after saturation was met, to ensure that overall frequency counts were an accurate representation of the cohort. Frequency analysis percentages reflect the number of times a topic was coded relative to the total number of codes; thus, this percentage provides an indication of the relative importance of each of the domains. Qualitative frequency analysis indicated that caregivers spent the most time discussing concerns with social health (44% of comments), followed closely by emotional health (40%), then by physical health (12%), and by cognitive health (3%). A detailed breakdown of the thematic content within each domain is summarized below and presented in Table 3.

### SOCIAL HEALTH

Caregivers most frequently discussed how being in a caregiving role has negatively affected their social health (44% of the discussion). Common concerns included trouble with finances, having to give up a career to serve as a caregiver for their service member (vocation), how being a caregiver has changed their social roles with both the person with the TBI and others (caregiver social role change), and how this change has also affected other social systems (including other family and friend relationships). Specifically, within the military system, many caregivers receive (or were applying for) caregiver stipends that allow them to be paid for providing care for the service member. This type of benefit generally precludes them from having another vocation, and often results in financial strain, as the caregiver stipend is almost always less money than the wages an individual would be able to garner when competitively employed. In addition, much of the discussion revolved around a change in social roles or social systems. Common themes among changes in social roles included having difficulty switching back and forth from the role of a spouse to that of a caregiver (“I didn’t anticipate being his parent and the next day – hour, I’m his spouse”), being uncertain of how hard to push the person with the injury (“it’s a struggle between how much you do and how much you don’t do), having to manage another person who was previously independent (“I think it’s hard to be like a brain for someone else”), and having to reprioritize and reevaluate what things were important (“I think that we’ve lowered our standards so low for a quality of life”). With regard to changing systems, common themes included family disruption (“has affected our family in ways that I had no idea it could”), being unable to do the things that were originally planned (“I feel this is not the place that I should be in at this time in my life”), and loss of friends (“I lost a whole circle of friends”).

### EMOTIONAL HEALTH

Caregivers also discussed how the caregiving role has affected their emotional health (40% of the discussion). The most commonly discussed concerns included caregiver strain/burden, feelings of loss (grief over things that have changed for the service member because of the injury, as well as grief related to self-sacrifice and having to give up things to care for the service member), feelings of anger (much of which was targeted at anger/frustration with the military and VA healthcare systems), depression, and anxiety. These caregivers also frequently discussed experiencing anxiety that was focused on having to be hypervigilant.



For example, caregivers expressed having to constantly monitor their own behavior, the behavior of other individuals, and the behavior of the service member in order to minimize upsetting their service member. Failure to do so might result in emotionally upsetting their service member, or even physical violence (directed at the caregiver or at other individuals). One caregiver commented “we’re constantly on guard of anywhere you go to eat or anywhere you go out...that it’s like okay, is this place going to be good for him?.”

Furthermore, caregivers frequently discussed living within the military culture, and how there were both internal and external pressures to maintain the appearances that things were okay even if they are not (“we’re taught... you don’t break down. So a lot of our emotions are hidden”). Positive aspects of being a caregiver were also discussed. There was a general feeling of pride and respect for the sacrifices that their loved one had made for their country; being able to care for this individual fostered individual pride (“we’re proud to be able to serve this way... just because he’s not serving in the same way...doesn’t mean that we’re not still serving our country”).

### **PHYSICAL/MEDICAL HEALTH**

Issues and concerns about changes in physical health were less common (12% of the discussion). Nonetheless, discussion of health behaviors (including lifestyle choices such as diet and exercise) as well as difficulties keeping up with their own medical care was a predominant focus within this domain. For some, the injury also negatively affected their intimacy/sexual life with their partners (“there’s no... intimacy left because he’s not able to even really communicate with me”). Fatigue and sleep difficulties were also common complaints.

### **COGNITIVE HEALTH**

Cognitive concerns were only occasionally discussed, and most likely were raised in response to direct inquiries from the moderators (3% of the discussion). Cognitive concerns were most frequently articulated as not feeling as “sharp” as s/he used to be (due to being overwhelmed by the caregiver role), and feeling like they had TBI via proxy (“it’s a joke in the caregiver community that TBI is contagious”).

### **Discussion**

This study highlights the different aspects of HRQOL that are affected by caring for a service member or veteran with TBI. With regard to social functioning, caregivers expressed concerns about finances (and the financial impact of having to give up a vocation to become a paid caregiver for their loved one), how TBI has resulted in changes in their social system (impacting the relationships they have with their service member), as well as the changes this had on the larger social network (including other family and friend relationships). All of these social concerns generally overlap and are consistent with those that were raised in similar focus groups in a civilian cohort.<sup>37</sup> With regard to finances and financial strain, the military caregivers frequently discussed military provided caregiver compensation; these caregivers lived in constant fear of losing these benefits. On the other hand, civilian caregivers do not have comparable caregiver stipend benefits (although caregivers may

receive monetary compensation through Medicaid; this was not raised as part of the civilian caregiver discussion). Discussion for civilian caregivers (with regard to finances and financial strain) focused more on loss of work (for both the caregiver and individuals with the TBI), as well as on how the medical expenses related to TBI treatment and rehabilitation affected them.

In addition to the social concerns that were raised, emotional concerns included caregiver strain/burden, feelings of loss, depression, and general anxiety, all of which were consistent with concerns raised by caregivers of civilian-TBI.<sup>37</sup> However, in contrast to civilian caregivers, caregivers of military TBI also frequently discussed concerns of hypervigilance, or having to constantly monitor and control the environment so as to avoid people and situations that might upset their service members. This concern was unique to military caregivers relative to civilian caregivers, who minimally discussed this topic.<sup>37</sup> We postulate that this difference (in military vs. civilian caregivers) is likely due to the high rates of comorbid posttraumatic stress disorder in this population.<sup>38</sup> Mild/prodromal posttraumatic stress symptomatology may be more pronounced in individuals with comorbid TBI. Specifically, individuals with comorbid TBI and posttraumatic stress may have a harder time coping with and managing the stressors associated with combat-related deployment(s). These individuals may also have a harder time readjusting to civilian life, or may have cognitive limitations that limit full participation in some psychotherapeutic modalities. Caregivers of service members with TBI also placed greater emphasis on emotional suppression (i.e., having to hide what they are really feeling), relative to their civilian counterparts.<sup>37</sup> This is consistent with work highlighting the unique aspects of military culture<sup>39,40</sup> and how any admitted weakness may result in a significant reduction in duties and responsibilities.<sup>40</sup>

Caregivers of service members with TBI also expressed a lot of anger. Although civilian caregivers also express anger,<sup>37</sup> the qualitative nature of this anger was different. Specifically, caregivers of military TBI articulated anger related to perceived lack of availability, accessibility, or ease of navigating the military or VA healthcare system. Difficulty qualifying for appropriate benefits, getting timely appointments, and disruption of financial benefits were common complaints and significant sources of anger for many caregivers. A lack of coordinated care for the caregiver and/or other family members was also a frequent source of caregiver anger. These complaints highlight areas where future improvements in accessibility or care navigation may be beneficial.

Finally, caregivers of service members with TBI also talked about the effects that caregiving has on both physical and cognitive health. Similar to caregivers of civilians with TBI,<sup>37</sup> these military caregivers discussed health behaviors, difficulty keeping up with their own medical care, changes in their sex lives, and problems with sleep and fatigue, as well as some limited discussion of how the stress of caring for someone negatively affects cognition.

While this work highlights the many effects that caring for someone with a military-related TBI can have on HRQOL, there are some study limitations. First, the majority of caregivers were spouses. We have previously discovered differences between parent and spouse caregivers of civilians with TBI<sup>41</sup> and differences by relationship type should be explored in



caregivers of military TBI. We also did not examine the impact that length of time providing care had on the caregiver role. We also did not collect data on where the caregiver/service member was receiving care (i.e., the DoD or VA healthcare system); therefore we are unable to draw specific conclusions about the origins of specific healthcare complaints. In addition, although we required medical documentation of TBI for the injured service member, we did not consistently have enough medical record documentation to confirm TBI severity (this was missing for 20% of our sample). Thus, future work is needed to examine the relationship among TBI severity and caregiver HRQOL. In addition, we did not consistently collect information about comorbidities. For example, although we assume that the comorbid rates of TBI and posttraumatic stress disorder are comparable to general rates within these returning service members, we do not have enough information to characterize this in our sample. Future work should examine how these common comorbidities and/or polytrauma affect HRQOL for these caregivers. Furthermore, although comparisons were made between civilian and military caregivers, inclusion criteria for these study samples were not identical. In particular, civilian caregivers had to be providing care for an individual with a moderate or severe TBI,<sup>42</sup> whereas military caregivers had to be providing care for an individual with a DoD-defined TBI (which includes mild TBI).<sup>29</sup> This deliberate departure for our military caregivers reflects the fact that the majority of military-related TBIs are of mild severity (i.e., 82.4%); to exclude mild TBI from a military sample would minimize the generalizability of findings for this population. Thus, differences among civilian and military caregivers may be due, in part, to the systematic differences between the TBI groups for whom these individuals are providing care. We also did not control for interviewer bias in our study. Finally, we employed a qualitative approach that was designed specifically for the development of new patient reported outcomes measures and relies more heavily on the relative importance of specific topic areas, rather than more traditional qualitative analysis approaches. Future analysis using these more traditional qualitative analysis approaches are underway and may yield a different pattern of findings; these more traditional approaches might highlight important differences for a number of the different demographic variables that were evaluated for our sample (e.g., respondent type, length of time in a caregiver role, how personal values interface with HRQOL).

## Conclusions

To our knowledge, this is the first study to employ a qualitative focus group methodology to examine HRQOL for caregivers of individuals with military TBI. While this work highlights a number of HRQOL issues that are common to both caregivers of service member TBI and caregivers of civilian TBI, it also highlights a number of factors that are unique to the military caregiver experience. In particular, caregiver hypervigilance, emotional suppression, and anger with regard to ease of access of military and/or VA health care or financial services are areas that warrant future investigation and intervention. Future work is needed to address the complicated issues that face these caregivers and the service members for whom they provide care. To this end, we are in the process of developing a new set of measures that captures these aspects of HRQOL for these caregivers. Ultimately, such work should target improving HRQOL for these service members and their families.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## List of Abbreviations

<b>TBI</b>	traumatic brain injury
<b>HRQOL</b>	health-related quality of life
<b>WRNMMC</b>	Walter Reed National Military Medical Center
<b>DoD</b>	Department of Defense
<b>VA</b>	Veterans Affairs

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**Table 1**

## Department of Defense and Veterans Affairs Classification for TBI documentation

Criteria	Mild#	Moderate	Severe
Structural imaging	Normal	Normal or abnormal	Normal or abnormal
Loss of Consciousness	0–30 minutes	> 30 minutes and < 24 hours	> 24 hours
Alteration of consciousness/mental state*	0–24 hours	> 24 hours	> 24 hours
Post-traumatic amnesia	0–1 day	> 1 and < 7 days	> 7 days
Glasgow Coma Scale (best available in first 24 hours)	13–15	9–12	< 9

# Abnormal structural imaging (e.g., Magnetic Resonance Imaging or Computed Tomography Scanning) attributed to the injury will result in the individual being considered clinically to have greater than mild injury.

\* Alteration of mental status must be immediately related to the head trauma. Typical symptoms include: looking/feeling dazed, confusion, difficulty thinking clearly or responding appropriately to mental status questions, and being unable to describe events immediately before or after the trauma event.

**Table 2**

Demographic data for the TBI-CareQOL participants (N = 45)

<u>Variable</u>	<u>Caregiver</u>
<b>Age(Years)</b>	
M (SD)	37.3 (9.6)
<b>Sex</b>	
Female	93
<b>Ethnicity</b>	
Hispanic or Latino	9
<b>Race (%)</b>	
Caucasian	84
African American	
Other	
Unknown	
<b>Relationship to Service Member</b>	
Spouse	73
Child	16
Parent	4
Other	7
<b>Time in Caregiver Role (Years)</b>	
M (SD)	4.4 (2.5)
<b>Service Member Age (Years)</b>	
M (SD)	34.6 (6.4)
<b><u>TBI Severity</u></b>	
Mild	49
Moderate	13
Severe	7
Penetrating	11
Unknown	20
<b><u>Service Branch</u></b>	
Army	67



<b>Variable</b>	<b>Caregiver</b>
Marine Corps	11
Army National Guard	7
Air Force	4
Army Reserves	4
Navy	4
Navy Reserves	2
<b>Active Duty</b>	
Yes	9
<b>Blast-related injuries</b>	
Yes	67
<b>Mechanism of Injury</b>	
Motor Vehicle Accident	42
Gunshot Wound	16
Thrown Against Object	13
Fall	7
Struck By Object	7
Multiple Mechanisms	9
Other	2
<b>Deployment-Related Injury</b>	
Yes – Combat-related	69
Yes – Non-Combat-related	13
No – Not Deployment-related	13
More than one option (multiple injuries)	4

*Note.* Entries in the table represent number of participants (percentage), unless otherwise specified.

Health-Related Quality of Life (HRQOL) Themes Generated Among Caregivers of Individuals with a Military-related Traumatic Brain Injury (TBI)

Table 3

HRQOL Domain and Subdomains	Example Quotation	Overall Thematic Breakdown	Results from civilian TBI caregivers <sup>37</sup>
<u>SOCIAL HEALTH</u>			
Finances	“And I mean, even at 100% rating, and getting your caregiver stipend, if you own a home and you have a car payment and you have bills, you’re not making ends meet”	(44%) 17	(42%) 9
Caregiver Social Role Change	“And most of the time I don’t see him as my husband. I see him as a child. As one of the kids”	15	(31) <sup>a</sup>
Informational Support	“There’s just not a lot of – I mean the resources are out there, but they’re not very helpful when you call them”	13	(31) <sup>b</sup>
Social System Change (family/friends)	“We’ve probably all lost a lot of close connections with family”	11	(31) <sup>a</sup>
Vocation	“So I had to leave my job and become his full-time caregiver”	9	7
Instrumental Support	“but most people don’t realize that, okay, yes, helping once a week, that’s awesome, but sometimes there’s people that need help like every single day”	8	(31) <sup>b</sup>
Emotional Support	“but there’s nobody for me as a caregiver to turn to”	6	(31) <sup>b</sup>
Community Life/Recreation	“I’m so proud to be part of the Wounded Warrior community”	5	7
Stigma	“Or we can go somewhere without my husband. But they don’t allow their children around my husband, even though they’ve never had any kind of experience or you know”	5	5
Companionship	“Yeah. And it’s always, you know if I want to cuddle on the couch, he wants nothing to do with me”	3	(31) <sup>b</sup>
Isolation	“I feel isolated. I feel isolated a lot”	3	6
<u>EMOTIONAL HEALTH</u>			
Caregiver Strain	“It’s just you kind of almost feel like you’re drowning trying to help them”	(40%) 20	(34%) 22
Feelings of Loss	“I think for my son, I just – it breaks my heart that at age 20 he had this horrible injury and his life will never be the same”	13	(9%) <sup>c</sup>
Anger	“I feel a lot of anger and resentment”	12	10
Depression/Self-esteem	“I mean it’s hard, I think, not to be depressed when you’re dealing with some of these things”	10	6
Positive emotions	“I’m very grateful every day I have my husband”	9	7
General Anxiety	“I have some anxiety issues and it all relates around his behavior”	7	5
Hypervigilance	“we’re very guarded-on guard a lot just to make sure that they’re okay”	7	-

HRQOL Domain and Subdomains	Example Quotation	Overall Thematic Breakdown	Results from civilian TBI caregivers <sup>37</sup>
Suppression	“How do you feel?” That’s a question I get a lot. “How do you feel?” I try not to.”	5	-
Emotional Roadblocks	“but I feel like I can’t be honest about what my needs are”	5 (12%)	6 (11%)
<u>PHYSICAL HEALTH</u>			
Health Behaviors	“And it really wasn’t even up till like two years ago – we’re eight years into this – that I started to do more work on myself, for my health”	20	27
Medical Care/Medication	“I was just put on depression meds”	15	20
Sexual Functioning	“Like you know, I don’t have those sexual thoughts in my head anymore”	14	6
Fatigue	“But then we’re also so exhausted at the end of each day”	12	8
Sleep	“I don’t sleep as well as I used to”	7	10
Pain	“I wake up in the morning with my jaw hurting because I’m just so tense”	4	5
GI Complaints	“because I have a stomach condition”	2	3
<u>COGNITIVE HEALTH</u>	“My memory issues are very, very problematic”	3 (3%)	(3%)

Note. Percentages for Domains reflect the total percentage of comments related to this specific domain (Domain percentages should sum to 100 with rounding); percentages within each Subdomains reflect the percentage of comments within each Domain (should sum to ~100). Results from civilian caregiver groups are published elsewhere<sup>37</sup> and are shown here for comparison purposes.

<sup>a</sup> = civilian analyses for role changes combines military concepts of caregiver social role change and social system change;

<sup>b</sup> = civilian analyses for companionship included the concepts of companionship, informational support, and instrumental support from the military analysis;

<sup>c</sup> = civilian analyses for feelings of loss were coded differently than the military analysis—this construct was coded as a separate, stand-alone content area, for the military analysis this construct was coded as a subcomponent of emotional health.