

A Needs Review of Caregivers for Adults With Traumatic Brain Injury

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A literature review of the stresses of caregivers of active-duty service members and veterans with a traumatic brain injury provides clinicians with the information and resources they can use in caring for this patient population.

Traumatic brain injury (TBI) is a health concern for the U.S. Military Health System (MHS) as well as the VHA. It occurs in both deployed and nondeployed settings; however, Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) and improved reporting mechanisms have dramatically increased TBI diagnoses in active-duty service members. According to the Defense and Veterans Brain Injury Center (DVBIC), more than 370,000 service members have been diagnosed with a TBI since 2000 (Figure).¹

BACKGROUND

The DoD and the VA are collaborating on clinical research studies to identify, understand, and treat the long-term effects of TBI that can affect patients and their families. Most TBIs are mild (mTBIs), also called concussions, and patients typically recover within a few weeks (Table 1). However, some individuals with mTBI experience symptoms that may persist for months or years. A meta-analysis by Perry and colleagues

showed that the prevalence or risk of a neurologic disorder, depression, or other mental health issue following mTBI was 67% higher compared with that in uninjured controls.²

Patients with any severity of TBI may require assistance with activities of daily living (ADLs), such as bathing, dressing, managing medications, and feeding. Patients also may need help with instrumental ADLs, such as meal preparation, grocery shopping, household chores, child care, getting to appointments or activities, coordination of educational and vocational services, financial and benefits management, and supportive listening.

Increased injuries have spurred the DoD and VA to coordinate health care to provide a seamless transition for patients between the 2 agencies. However, individuals who sustained a TBI may need various levels of caregiver assistance over time.

TBI and Caregivers

Despite better agency coordination for patients, caregivers can experience stress. Griffin and colleagues found that caregiving responsibilities can compete with other demands on the caregiver, such as work and family, and may negatively impact their health and finances.^{3,4}

Lou and colleagues studied the factors associated with caring for

chronically ill family members that may result in stress for the caregivers.⁵ Along with an unaccounted for economic contribution, caregivers may face lost work time and pay and limitations on work travel and work advancement. Additionally, lost time for leisure, travel, social activities, family obligations, and retirement could result in physical and mental drain on the caregiver. Stress may reach a level at which the caregivers risk psychological distress. The study also noted that families with perceived high stress experience disrupted family functioning. Some TBI caregiver studies sought to understand how best to evaluate and determine the level of caregiver burden, and other studies investigated appropriate interventions.⁶⁻⁹

Health care practitioners within the federal health care system may benefit from a greater awareness of caregiver needs and caregiver resources. Caregiver support can improve outcomes for both the caregiver and care recipient, and many organizations and resources already exist to assist the caregiver. This article reviews recent published literature on TBI caregivers of patients with TBI across civilian, military, and veteran populations and lists caregiver resources for additional information, assistance, and support.

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LITERATURE REVIEW

The DVVIC defines the term caregiver as “any family or support person(s) relied upon by the service member or veteran with traumatic brain injury (TBI) who assumes primary responsibility for ensuring the needed level of care and overall well-being of that service member or veteran. A family or family caregiver may include spouse, parents, children, other extended family members, as well as significant others and friends.”³

In the following discussion, findings from military and veteran literature are separated from civilian population findings to highlight similarities and differences between these 2 bodies of research. Several of the studies in the military/veteran cohorts include polytrauma patients with comorbid physical and mental health issues not necessarily found in civilian literature.

Civilian Literature

A 2015 systematic review by Anderson and colleagues on coping and psychological adjustment in TBI caregivers indicated no Class I or Class II studies.¹⁰ Four Class III and 3 Class IV studies were found. The authors suggest that more rigorous studies (ie, Class I and II) are needed.

Despite these limitations, peer-reviewed literature indicates that the levels of stress and distress in TBI caregivers are consistent with reports for other diseases. In a civilian population, Carlozzi and colleagues found that TBI caregivers who reported stress, distress, anxiety, and feeling overwhelmed often had concerns for their social, emotional, physical, cognitive health, as well as feelings of loss.⁵ In addition, caregivers may need to take leaves of absence or leave the workforce entirely to provide for a family member or friend who had

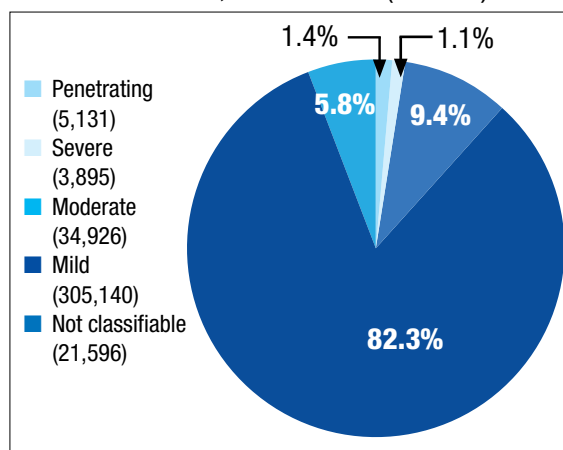
a TBI—often leading to financial strain (eg, depleting assets, accumulating debt). These challenges may occur during prime earning years, and the caregiver may lose the ability to resume work if the care receiver requires care for extended periods.¹¹

Kratz and colleagues showed that caregivers of individuals with moderate-to-severe TBI: (1) felt overburdened with responsibilities; (2) lacked personal time and time for self-care; (3) felt their lives were interrupted or lost; (4) grieved the loss of the person with TBI; and (5) endorsed anger, guilt, anxiety, and sadness.¹²

Perceptions differed between caregiver parents and caregiver partners. Parents expressed feelings of grief and sadness related to the “loss of the person before the TBI.” Parents also reported a sense of guilt and responsibility for their child’s TBI and feelings of being tied down to the individual with TBI. Parents experienced a greater level of stress if the son or daughter with TBI still lived at home. Partners expressed frustration and despair related to their role as sole decision maker and care provider. Partners’ distress also related to the partner relationship and the relationship between children and the individual with TBI.

Verhasghe and colleagues found that partners experience a greater degree of stress than do parents.¹³ Young families with minimal social support for coping with financial, psychiatric, and medical problems were the most vulnerable to stress. A systematic review by Ennis and colleagues evaluated depression

Figure. DoD Traumatic Brain Injuries Worldwide Total, 2000-2017 (Q1-Q2)



and anxiety in caregiver parents vs spouses.¹⁴ Although methods and quality differed in the studies, findings indicated high levels of distress regardless of the type of caregiver.

Anderson and colleagues used the Ways of Coping Questionnaire to evaluate the association between coping and psychological adjustment in caregivers of TBI individuals.¹⁰ The use of emotion-focused coping and problem solving was possibly associated with psychological adjustment in caregivers. Verhasghe and colleagues indicated that the nature of the injuries more than the severity of TBI determined the level of stress up to 15 years after the TBI.¹³ Gender and social and professional support also influenced coping. The review identified the need to develop models of long-term support and care.

An Australian cohort of 79 family caregivers participated in a study by Perlesz and colleagues.¹⁵ Participants’ caregiving responsibilities averaged 19.3 months posttrauma. The Family Satisfaction Scale, Beck Depression Inventory, State Anxiety Inventory, and Profile of Mood States were used in this analysis. Male caregivers reported distress in terms of anger

and fatigue; female caregivers were at greatest risk of poor psychosocial outcomes. Although findings from primary caregivers indicated that 35% to 49% displayed enough distress to warrant clinical intervention, between 51% and 80% were not psychologically distressed and were satisfied with their families. Data supported previous reports suggesting caregivers are “not universally distressed.”¹⁵

Manskow and colleagues followed patients with severe TBI and assessed caregiver burden 1 year later. Using the Caregiver Burden Scale, caregivers reported the highest scores (N = 92) on the General Strain Index followed by the Disappointment Index.¹⁶ Bayen and colleagues also studied caregivers of severe TBI patients.¹⁷ Objective and subjective caregiver burden data 4 years later indicated 44% of caregivers (N = 98) reported multidimensional burden. Greater burden was associated in caring for individuals who had poorer Glasgow Outcome Scale Extended scores and more severe cognitive disorders.

Military and Veteran Literature

Griffin and colleagues conducted the Family and Caregiver Experience Study (FACES) with caregivers (N = 564) of service members who incurred a TBI.³ According to the caregivers, two-thirds of the patients lost consciousness for more than 30 minutes, which was followed by inpatient rehabilitation care at a VA polytrauma center between 2001 and 2009. The majority of caregivers of TBI patients were female (79%) and aged < 60 years (84%). Parents comprised 62% and spouses 32% of the cohort. Caregivers tended to have some level of education beyond high school (73%), were married (77%), either worked or were enrolled in school (55%), and earned

less than \$40,000 a year (70%). Common characteristics of the care receivers were male gender (95%), average age 30, high school educated (52%), married (almost 50%), and employed (50%). Forty-five percent of the care receivers were injured 4 to 6 years prior, and 12% were injured 7 or more years prior. The study determined the caregivers’ perception of intensity of care needed and indicated that families as well as clinicians need to plan for some level of long-term support and services.

In addition to the TBI-related caregiving needs, Griffin and colleagues found in a military population that other medical conditions impacted the level of caregiving and strained a marriage.¹⁸ Their study found that in a military population between 30% and 50% of marriages of patients with TBI dissolved within the first 10 years after injury. Caregivers may need to learn nursing activities, such as tube feedings, tracheostomy and stoma care, catheter care, wound care, and medication administration. Family stress with caregiving may interfere with the ability to understand information related to the care receivers’ medical care and may require multiple formats to explain care needs. Sander and colleagues associated better emotional functioning in caregivers with greater social integration and occupation outcomes in patients at the postacute rehabilitation program phase (within 6 months of injury).¹⁹ However, these outcomes did not continue more than 6 months postinjury.

INTERVENTION AND RESEARCH STUDIES

Powell and colleagues used a telephone-based, individualized TBI education intervention along with problem-solving mentoring (10 phone calls at 2-week inter-

vals following patient discharge for moderate-to-severe TBI from a level 1 trauma center) to determine which programs, activities, and coping strategies could decrease caregiver challenges.²⁰ The telephone interventions resulted in better caregiver outcomes than usual care as measured by composite scores on the Bakas Caregiving Outcomes Scale (BCOS) and the Brief Symptom Inventory (BSI-18) at 6 months post-TBI survivor discharge. Dyer and colleagues explored Internet approaches and mobile applications to provide support for caregivers.¹⁸ In a small sample of 10 caregivers, Damianakis and colleagues conducted a 10-session pilot videoconferencing support-group intervention program led by a clinician. Results indicated that the intervention enhanced caregiver coping and problem-solving skills.⁷

Petranovich and colleagues examined the efficacy of counselor-assisted problem-solving interventions in improving long-term caregiver psychological functioning following TBI in adolescents.²¹ Their findings support the utility of online interventions in improving long-term caregiver psychological distress, particularly for lower income families. Although this study focused on adolescents, research may indicate merit in an adult population. In relatives of patients with severe TBI, Norup and colleagues associated improvements in health-related quality of life (HRQOL) with improvements in symptoms of anxiety and depression without specific intervention.²²

Moriarty and colleagues conducted a randomized controlled trial for veterans who received care at a VA polytrauma center and their family members who participated in a veteran’s in-home program (VIP) intervention.⁹ The study aimed to evaluate how VIP affected family

members' caregiver burden, depressive symptoms, satisfaction with caregiving, and the program's acceptability. Eighty-one veterans with a key family member were randomized. Of those, 63 veterans completed a follow-up interview. The intervention consisted of 6 home visits of 1 to 2 hours each and 2 telephone calls from an occupational therapist over 3 to 4 months. Family members were invited to participate during the home visits. The control group received usual clinic care with 2 telephone calls during the study period. All participants received the follow-up interview 3 to 4 months after baseline interviews. The severity of TBI was determined by a review of the electronic medical record using the VA/DoD Clinical Practice Guidelines. Findings of this study indicated that family members in the intervention group showed significantly lower depressive symptom scores and caregiver burden scores.⁹ Additionally, the veterans in the intervention group exhibited higher community integration and ability to manage their targeted outcomes. Further research may indicate that VIP could assist patients with TBI and caregivers in an active-duty population.

The DVBIC is the executive agent for a congressionally mandated 15-year longitudinal study on TBI incurred by members of the armed services in OEF and OIF. The John Warner National Defense Authorization Act for Fiscal Year 2007 outlined the study. An initial finding identified the need for an HRQOL outcomes assessment specific to TBI caregivers.²³ Having these data will allow investigators to fully determine the comprehensive impact of caring for a person who sustained a mild, moderate, severe, or penetrating TBI and to evaluate the effectiveness of interventions designed to address

Table 1. Traumatic Brain Injury Severity^a

Criteria ^b	Mild	Moderate	Severe
Structural imaging	Normal	Normal or abnormal	Normal or abnormal
Loss of consciousness	≤ 30 min	> 30 min - 24 h	> 24 h
Alteration of consciousness / mental state ^c	Up to 24 h	> 24 h; severity based on other criteria	
Posttraumatic amnesia	≤ 1 d	> 1 and < 7 d	> 7 d
Glasgow Coma Scale (best available score in first 24 h) ^d	13-15 h	9-12 h	< 9 h

^aFind the DoD/VA TBI severity classification guidelines at www.dvbic.dcoe.mil.

^bIf a patient meets criteria in more than 1 category of severity, the higher severity level is assigned.

^cAlteration of mental status must be immediately related to the trauma to the head. Typical symptoms would be looking and feeling dazed and uncertain of what is happening, confusion, difficulty thinking clearly or responding appropriately to mental status questions, and being unable to describe events immediately before or after the trauma event.

^dIn April 2015, the DoD released a memorandum recommending against the use of Glasgow Coma Scale to diagnose traumatic brain injury. See the memorandum for additional information.

caregivers' needs. To date, the study has identified the following HRQOL themes generated among caregivers: social health, emotional health, physical/medical health, cognitive functioning, and feelings of loss (related to changing social roles). Carlozzi and colleagues noted that the study also aimed to identify a sensitive outcome measure to evaluate quality of life in the caregivers over time.⁷

KNOWLEDGE GAPS

Ongoing studies focus on caregiving for individuals with various illnesses and needs. Some of the information in each study may be beneficial to TBI caregivers who are not fully aware of resources and interventions. For example, Fortune and colleagues, Hirano and colleagues, and Grover and colleagues are studying caregiver activities involving other diseases to determine, more generally, which programs, activities, and coping strategies can decrease caregiver challenges.²⁴⁻²⁶ Further, understanding and addressing the needs of

these families over many years will provide data that could inform policy, benefits, resources, and needed services (such as the Caregivers and Veterans Omnibus Health Services Act of 2010) and assist with family resilience efforts, including understanding and enhancing family protective and recovery factors.

As studies have indicated, some families do not report family distress when providing care to an individual with TBI. Understanding the factors that influence positive family adjustment is important to capture and perhaps replicate in future studies so that they can lead to effective treatment interventions. Although this review does not discuss caregiver needs for patients with TBI with disorders of consciousness that require more care than most caregivers can provide in the home setting, caregiving for this population deserves attention in future studies. Furthermore, an area that has not received much attention is the impact on children in the household. Children aged < 18 years

Table 2. Caregiver Resources

Name	Resource	Website
AARP	Online seminars and educational resources	www.aarp.org/caregiver/home.html
AARP Care Connections	Education, community resources, connect with other caregivers	Careconnection.aarp.org
Blue Star Families	Support and resources for military families of active-duty service members	bluestarfam.org
Brain Injury Association of America	Education, research, advocacy	www.biausa.org
Caregiving	Caregiver network, webinars, education	www.caregiving.com
Caregiver Action Network (previously National Family Caregiver Association)	Forums, peer networks, tool box, resources, and advocacy	www.caregiveraction.org
Caregiver's Journey	Traumatic brain injury guide for caregivers of service members and veterans	www.traumaticbraininjuryatoz.org
Defense and Veterans Brain Injury Center	Traumatic brain injury caregiver guide	dvbic.dcoe.mil/sites/default/files/Family/%20Caregiver%20Guide .
Department of Defense Warrior Care	Resources and information for military caregivers	warriorcare.dodlive.mil/caregiver-resources
Department of Veterans Affairs	Caregiver support program and services	www.caregiver.va.gov
Easter Seals Caregiver Training Program	Caregiver training classes	www.easterseals.com
Elizabeth Dole Foundation — Caring for Military Families	Caregivers advocacy program	www.elizabethdolefoundation.org
Empowering Caregivers	Newsletters, articles, resources	www.care-givers.com
Familycare America	National caregivers library	www.familycareamerica.com
Family Caregiver Alliance National Center on Caregiving	Caregiver resources, education, telephone conferences	www.caregiver.org/caregiver/jsp/home.jsp
Healthy Caregiver	Community-based outreach, education, and research	www.healthycaregiver.com

can assist not only in the care of a disabled adult, but also of younger siblings; also they can help with household activities from housekeeping to meal preparation. Children also may provide physical and emotional support.

The impact of aging caregivers and subsequent needs for their own care as well as the person(s) they are providing care for has not been fully addressed. Areas requiring more research include both the aging caregiver taking care of an aging spouse or relative and the aging parent tak-

ing care of a young adult or child. Along with aging, the issue of long-term caregiving needs further development. For example, how do the differences between access to services between caregivers of adults with TBI in the military and those in the civilian sector impact the family/caregiver? Further research may answer questions such as:

- Which tools are most useful in evaluating and determining caregiver stress and burden?
- Are the needs of military and veteran caregivers unique?

- Do polytrauma patients with comorbid diagnoses have unique caregiver needs and trajectories?
- Do TBI caregiver stressors differ from stressors related to other medical conditions or chronic diseases?
- Is there a need for military and veteran TBI-specific caregiver programs?
- Which interventions best help caregivers and for how long?
- Should the approach to intervention depend on variables such as age and gender of the

Table 2. Caregiver Resources (continued)

Name	Resource	Website
Hidden Heroes	Community resources, online caregiver courses, peer support	hiddenheroes.org
Military Family Caregiving Online Training	Online training for caregiving skills, tips, and resources	www.extension.org/militaryfamilies
Military and Veteran Caregiver Network	Resource library, online and community support	milvetcaregivernetwork.org
National Alliance for Caregiving	Education, advocacy, research, resources	www.caregiving.org
National Family Caregivers Association	Education, peer support, resources	www.nfca.org
National Family Caregivers Support Program	State grants to support caregivers	www.aoa.acl.gov
National Military Family Association	Assistance in navigating DoD and VA programs and benefits	www.militaryfamily.org/get-info/caregiver/transition-to.../caregivers-resources.html
Net of Care	Information and resources for caregivers	www.netofcare.org
Network of Care	Community resources and tools for caregivers	www.networkofcare.org
Operation Family Caregiver	Support for caregivers of post-9/11 service members	www.rosalynncarter.org/returning_soldiers
Operation Homefront	Online support for caregivers; financial relief	www.operationhomefront.net
Quality of Life Foundation	Caregiver support	qolfoundation.org
Rosalynn Carter Institute for Caregiving	Caregiver training mentor programs, advocacy, education, research	www.rosalynncarter.org
Today's Caregiver magazine	News and stories for caregivers	www.caregiver.com
United Service Organization (USO)	Caregiver seminars	www.uso.org
Veteran Caregiver	Peer-to-peer support for caregivers and veterans	www.veterancaregiver.com
Well Spouse Foundation	Advocacy, peer support, education for spousal caregivers	www.wellspouse.org
Wounded Warrior Project	Resource center, benefits assistance	www.woundedwarriorproject.org

caregivers or relationship to the patient with a TBI (eg, spouse vs parent)?

Methods or processes to inform and update caregivers about available resources also are critically needed. Also, Sabab and colleagues noted the importance of research on the effects of denial as it relates to cognitive, emotional, social impact.²⁷ Denial may impact delays in treatments.

RESOURCES

Many national, state, local, and grassroots organizations provide informa-

tion and support for persons with illness and/or disabilities. Most clinicians of neurologic, mental health, and cancer have developed various forms of support interventions for those with the disease and their caregivers (Table 2). Highlighted in this section are a few organizations that specifically provide resources for caregivers caring for active-duty service members or veterans with a TBI.

Although a caregiver generally does not receive money from an outside source for services, the DoD may consider the caregiver as a non-

medical attendant for an active-duty service member and provide a temporary stipend. The VA provides several support and service options for caregivers under the Caregiver Support Program, through which more than 300 VA health care professionals provide support to caregivers. The Caregivers and Veterans Omnibus Health Services Act of 2010 authorizes the VA to provide additional VA services for seriously injured post-9/11 veterans and their family caregivers through the Program of Comprehensive Assistance for

Family Caregivers (VA Caregiver Support Program). After meeting eligibility criteria, primary caregivers of post-9/11 veterans may receive a monthly stipend (based on the level of care needed) as well as comprehensive caregiver training, referral services, access to health care insurance, mental health services, counseling, and respite care. The Caregiver Support Program offers a toll-free support line and a 24-hour crisis hot line.

In 2014, the Government Accountability Office (GAO) outlined the VA health care improvements needed to manage the demand for the Caregiver Support Program, which are established at VA medical centers.²⁸ The GAO reported that the “VA significantly underestimated caregivers’ demand for services... larger than expected workloads and ...delays in approval determinations” with about 500 approved caregivers who are added to the program each month. Original estimates indicated that about 4,000 caregivers would be approved by September 2014; however, by May 2014 about 15,600 caregivers were approved.

In addition to the VA Caregiver Support Program, a variety of state, local, and nonprofit organizations offer support for caregivers. Established in 2012, the Elizabeth Dole Foundation’s program Caring for Military Families “assists caregivers by raising awareness of the caregiver role, leveraging resources and partnerships to provide support, and identifying best practices and solutions to address the challenges caregivers face.” The foundation commissioned the RAND Corporation to “describe the magnitude of military caregiving in the United States, and to identify gaps in programs, policies, and services.” The 2014 RAND report estimated that

among the 5.5 million military caregivers in the U.S., 1 million (19.6%) cared for post-9/11 veterans.²⁹ The military caregivers consistently experienced poorer health outcomes, greater strains on family relationships, and more workplace problems than noncaregivers; post-9/11 military caregivers fared worse in those areas.

The Elizabeth Dole Foundation, Hidden Heroes Impact Council Forum advocates for caregiver empowerment, cultural competency awareness, and better policies, programs, and services. The council focuses its efforts on key impact: community support at home, education and training, employment and workplace support, financial and legal issues, interfaith action and ministry council, mental and physical health, and respite care. It aims to raise the money to build awareness and support for military and veterans’ caregivers. The Military and Veteran Caregiver Network is another Elizabeth Dole Foundation initiative. It is an online forum community, peer support group, and peer mentor program structure. A resource library for referrals to local services also is available.

A variety of other organizations, such as United Service Organizations; Easter Seals; Team Red, White and Blue; Operation Homefront; Blue Star Families; state Brain Injury Associations; and support groups for TBI at local hospitals and community centers provide resources to both patients and caregivers. Organizations for caregivers not exclusive to TBI patients include the Caregiver Action Network (formerly National Family Caregiver Association) and the Family Caregiver Alliance. The National Family Caregivers Support Program provides grants to states and territories to develop and pro-

vide supportive services to caregivers. Some training for caregivers could include long-term financial planning, legal issues, residential and educational planning, caregiver stress management, the benefits of utilizing support resources, and actions and behaviors that enhance coping strategies. In 2007, DVVIC developed The Traumatic Brain Injury Guide for Caregivers of Service Members and Veterans, which is intended for family caregivers assisting a service member or veteran who sustained a moderate or severe TBI.⁶ A recent assessment determined the need to update the guide. The Center of Excellence for Medical Multimedia is another source of information for caregivers.

CONCLUSION

The recent combat conflicts of OEF and OIF have resulted in a dramatic increase in the occurrence of TBI injuries in active-duty service members both in theater and stateside and have highlighted the need for some service members and veterans with a TBI to require ongoing assistance from a caregiver. The levels of assistance and length of time vary greatly, impacted by the severity of the TBI and psychosocial situations.

In response to elevated awareness, several programs and resources have been developed or enhanced to address the specific needs of caregivers. Certain programs and resources are specific for caregivers of military service members and veterans, whereas others benefit caregivers in general. Likewise, some programs are not specific to individuals with TBI.

Caregivers assume many roles in their efforts to support the person with a TBI. They may need to dramatically adjust their lives to serve as a caregiver. Providing adequate resources for the caregivers impacts

their ability to continue providing care. Thus, awareness of and access to resources play a critical role in helping to reduce stress, distress, burden (eg, physical, emotional, and financial), and caregiver burnout. Programs and resources often change, making it difficult for health care practitioners to know which programs offer what or even whether they still exist. Therefore, the authors synthesized the current medical literature of the topic of TBI and their caregiver needs as well as current resources for additional information and support.

Ongoing research studies, such as the congressionally mandated 15-year longitudinal study, are examining the impact of caregiving in the military and veteran communities. Future research could identify specific needs of military caregivers, identify gaps in services or programs, and identify interventions that promote resilience. Moreover, research directed at military and veteran caregivers can promote change that will benefit the general population of caregivers. It will be important for health care practitioners to keep abreast of new findings and information to incorporate into care plans for their patients who have had a TBI and their families. ●

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Disclaimer

The opinions expressed herein are those of the authors and do not necessarily reflect those of Federal Practitioner, Frontline Medical Communications Inc., the U.S. Government, or any of its agencies.

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