



\*Photo Courtesy of James A. Haley Veterans Hospital & HDR Architecture, INC.

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# VA TBI Model Systems/IMAP Newsletter Caregiver Needs

## Development of the Caregiver and Family Special Interest Group .....

**A caregiver is someone who provides direct assistance to a person who is disabled or otherwise has limitations in completing activities of daily living, such as a person with traumatic brain injury (TBI). Caregivers are often spouses, significant others, parents, adult children, and other relatives.**

TBI has a significant impact on caregivers and family. They can have work disruptions, financial strain, marital distress, social isolation, increased stress, anxiety and depression, and reduced quality of life. Families of active duty Service Members spend extended time periods with their loved one at rehabilitation settings which are far from home. This results in limited access to familiar support networks. Much of the knowledge about caregiver needs arose from research by our colleagues from the civilian TBI Model Systems (TBIMS) program, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). It is crucial that we better understand how TBI impacts military families. Toward this end, in December of 2015, VA and NIDILRR colleagues partnered to create a Caregiver and Family Special Interest Group (SIG) within the TBIMS network. We aim to explore areas of needed research to address caregiver and family issues related to TBI. This collaborative partnership has already resulted in acceptance of two scientific papers (published in the *Journal of Head Trauma Rehabilitation* and described inside this newsletter). The SIG will work on developing treatments to reduce caregiver distress and improving family functioning. Ultimately, we hope that by better understanding the needs of caregivers of Veterans and Service Members with TBI, our findings can be used to better tailor services and benefits offered by the VA.



**Dr. Lillian Flores Stevens (Left) and Dr. Angelle Sander (Right) who are responsible for creating the TBI Model Systems Caregiver Special Interest Group.**

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**\* Flip to Page 4 to read our “Thank You” to our Participants and Caregivers!**

## 35% of Veterans and Service Members with TBI have supervision needs following discharge from inpatient rehabilitation.



**Dr. Erin K. Bailey** from the Miami VA Medical Center, lead author.

Individuals with supervision needs require adult caregivers to provide oversight to promote safety and assist with functional tasks due to cognitive, physical, and behavioral impairments following TBI. Therefore, supervision remains an important factor when considering rehabilitation outcome. However, there is a lack of research describing supervision needs following TBI in military and veteran populations. This study characterizes supervision needs at

1 year post-injury and explore predictors of supervision needs among Veteran and Service Members. Of the 302 participants, 35% had supervision needs following rehabilitation discharge. Those who had a more severe TBI, had worse functional impairments and were married, reported greater supervision needs. When we evaluated the impact of selected risk factors, age at injury and duration of Posttraumatic Amnesia were significantly associated with supervision needs. We also examined differences in reported supervision needs depending on the participant's place of residence at 1 year after injury. Individuals in an institutional or hospital setting were more likely to need supervision, (20% and 26% increase respectively) compared to those in a private residence.

**Individuals with supervision needs require adult caregivers to be in the physical vicinity of the patient to assist with functioning and to ensure safety.**

This is the first study to identify predictors of supervision needs at one year post-TBI in a veteran and military population. This is also the first study to examine supervision by type of residential settings in this population, highlighting the importance of context of recovery for military and veterans with TBI. The Veterans Affairs Polytrauma System of Care offers several training and education opportunities, as well as financial benefits and mental health resources, to caregivers of Service Members and Veterans with TBI. The findings of this study confirm supervision needs as a chronic feature of moderate and severe TBI and lend support to the continued allocation of resources to caregivers after injury.

Reference: Bailey EK, Nakase-Richardson R, Dillahunt-Aspillaga C, Patel N, Ropacki S, Sander AM, Stevens L, Tang X. Supervision needs following moderate to severe Veteran and Service Member Traumatic Brain Injury: A VA TBIMS Study. *J Head Trauma Rehabil.* 2017; 32(4): 245-254.

## About Our Projects

### TBIMS

**VA Traumatic Brain Injury Model Systems (TBIMS)** is a longitudinal multi-center research program that examines TBI outcomes among Veterans and Military Personnel following comprehensive inpatient rehabilitation. The goal of TBIMS is to conduct research that contributes to evidence-based rehabilitation interventions and practice guidelines that improve the lives of individuals with TBI.

### IMAP

**Improved Understanding of Medical and Psychological Needs in Veterans and Service Members with TBI (IMAP)** is an extension of TBIMS. The goals of IMAP are to examine types of long-term physical and mental health conditions in persons with TBI, the impact of comorbid health conditions on recovery, and chronic rehabilitation needs including accessibility of needed services.

**\*Principal Investigator for TBIMS/IMAP: Dr. Risa Nakase-Richardson**

## Recent and Upcoming Presentations

TBIMS/IMAP investigators will be presenting numerous studies at the following upcoming conferences and meetings.

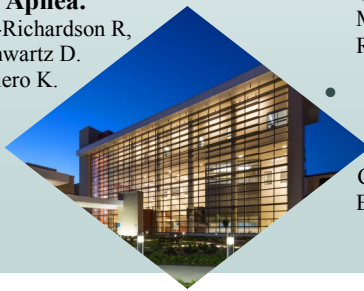
Annual Meeting of the Associated Professional Sleep Societies, held in Boston, Massachusetts - June 2017.

- **Sleep Apnea Severity is associated with Motor Recovery and Processing Speed in Acute TBI Rehabilitation Admissions**

Nakase-Richardson R, Healey E, Silva M, Schwartz D, Modarres M, Brown R, Lim M

- **Sleep Stages, Total Sleep Time, and Arousals in Acquired Brain Injury Rehabilitation Patients with and without Sleep Apnea.**

Silva M, Nakase-Richardson R, Smith NDW, Schwartz D, Anderson W, Calero K.



Military Health System Research Symposium, to be held in Kissimmee, Florida - August 2017.

- **Do civilian epidemiologic studies inform military TBI epidemiology? A comparison of the VA and NIDILRR TBI Model System cohorts.**

Nakase-Richardson R, Stevens LF, Tang X, Lambert GJ, Sherer M, Walker W, Pugh MJ, Eapen BC, Finn JA, Dillahunt-Aspillaga C, Adams RS, Garafano JS.

- **Employment stability in Veterans and Service Members with TBI.**

Cotner BA, Dillahunt-Aspillaga C, Pugh MJ, Silva MA, Haskin AA, Tang X, Saylor M, Nakase-Richardson R.

- **Suicide-related ideation and attempts at 1-year post traumatic brain injury**

Dreer LE, Tang X, Nakase-Richardson R, Pugh MJ, Cox MK, Bailey E, Finn J, Zafonte R, Gowen MS, Brenner LA.

American Congress of Rehabilitation Medicine Conference, to be held in Atlanta, Georgia - October 2017.

- **Exploring the association between sleep and BMI in veterans with traumatic brain injury.**

Brown RM, Nakase-Richardson R, Tang X, Silva MA, Larosa K, McKenzie-Hartman T, Schwartz D, Modarres M.

- **Instructional Course: Improving recognition and treatment of sleep apnea in the rehabilitation setting.**

Nakase-Richardson R, Schwartz D, Calero K, Modarres M, Bell K, Monden K.

- **Sleep Apnea Treatment Adherence in a VA TBI Model Systems Cohort: A Feasibility Study.**

Cool D, Schwartz D, Calero K, Nakase-Richardson R, LaRosa K, Silva M.

## Most Veterans and Military Service Members have stable marital relationships following a TBI, but some experience marital breakdown.

Lead Author, Dr. Lillian Flores Stevens and colleagues examined relationship instability in 357 Veterans and Service Members with a TBI. They were followed for two years after their injury.

### FINDINGS

Of the 151 Veterans and Service Members who were married at the time of injury, 78% remained married two years later. However, 22% experienced marital breakdown – that is, they were separated or divorced after two years. Some information about Veterans and Service Members was associated with marital breakdown. Specifically, Veterans and Service Members who became separated or divorced were more likely to be younger at time of injury, have a lower education level, and have a history of mental health treatment prior to their TBI. In contrast, 206 were single (never married), separated, or divorced prior to their TBI. Of these, 13% were married within two years. Those who were injured while deployed were more likely to get married.

Reference: Stevens LF, Lapis Y, Tang X, Sander AM, Dreer LE, Hammond FM, Kreutzer J, O'Neil-Pirozzi TM, Nakase-Richardson R. Relationship stability after traumatic brain injury among veterans and service members: A VA TBI Model Systems study. *J Head Trauma Rehabil.* 2017; 32(4): 234-244.

### WHAT DOES THIS MEAN?

This study identified factors linked to marital breakdown after TBI. This knowledge will help rehabilitation providers identify which Veterans and Service Members are at risk. They may benefit from personalized intervention to strengthen the marital relationship. Couples/marital counseling could be prioritized as part of Polytrauma rehabilitation, particularly for Veterans and Service Members who are younger, less educated, and have a mental health history. Identifying at-risk couples early and getting them into counseling may better prepare them for navigating marital problems post-TBI. Future research should explore other factors that predict relationship stability and positive relationship change, such as resilience and conflict management.

## Thank You For Your Participation!

Thank You to our Veterans, Service Members, and their caregivers for volunteering your time to participate in TBI Model Systems and IMAP research. Your time completing interviews and questionnaires for this research has resulted in scientific papers that inform military and VA healthcare policy. In July of 2017, a special issue in the *Journal of Head Trauma and Rehabilitation* featuring studies from this research program will be highlighted with commentary from the VA Rehabilitation National Director, Dr. Joel Scholten, highlighting the value for informing the evolution of the Polytrauma System of Care. The entire research team appreciates your dedication to this project, which will help improve healthcare for all Veterans, Service Members and caregivers of those with TBI. As of June 30, 2017, there were 1063 veterans and military personnel enrolled in the legacy VA TBI Model Systems research study. **Thank you!** - Risa Nakase-Richardson, PhD.

## Participant Recruitment Celebration at James A. Haley Veteran's Hospital!

We are moments away from recruiting our 500th participant into the VA TBI Model Systems research study at the Tampa VA Hospital. To celebrate this benchmark, we are holding an informational day for our Veterans and Staff to learn more about our research findings. It will be held in November 2017. **Please join us!**

## Caregiver Resources

- **Traumatic Brain Injury A-to-Z The Caregiver's Journey**  
Learn about TBI, managing effects, how to advocate, take care of yourself, and learn how to take care of family matters.  
**TraumaticbraininjuryAtoZ.org**
- **TBI Community Resources**  
Visit this website to find a variety of resources and publications that will help Caregivers and Consumers that are dealing with TBI.  
**TBICommunity.org/Resources**
- **Relationships after TBI, Factsheet and Video**  
This resource features many videos and a factsheet on Relationships after Traumatic Brain Injury.  
**MSKTC.org/TBI**
- **Past Versions** of the Newsletter can be found at the following Website  
**VA.TBINDSC.ORG/Default**
- **The TBI Family Podcast Series.**  
Podcast series for caregivers of Veterans and Service Members with TBI. Offers information, resources, and tips.  
**DVBIC.dcoe.mil/Podcasts**
- **DoD Warrior Care Caregiver Resources**  
Military caregiver resources. Included PEER Forums, Webinars and Events, and an in-depth Caregiver Resource Directory.  
**WarriorCare.DoDLive.Mil/Caregiver-Resources**
- **ARCH National Respite Network**  
This resource will provide respite services in your area with a quick search!  
**ARCHRespite.org**
- **VA Caregiver Support**  
Find a Caregiver Tool Box, Free Work Shop, Caregiver Connections, Training and additional helpful resources.  
**Caregiver.va.gov**
- **Elizabeth Dole Foundation**  
The Elizabeth Dole Foundation mission is to reach out to military caregivers to empower, support, and honor them. Founded in 2012, the foundation works with public, private, nonprofit, labor and faith communities to promote the well-being of military caregivers. They offer support in a couple of different ways, one being the Hidden Heroes Caregiving Community.  
**Hidden Heroes Caregiving Community** - This is an online support group in which military caregivers can connect with one another to find advice, share their stories, and feel less alone in their daily challenges. Military caregivers can register and receive more helpful information through the website:  
**HiddenHeroes.org**

## Contact Information

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