

TBI TODAY

News, Ideas, and Resources from the Virginia TBI Model System

Sources of Caregiver Support: Early Findings

by Drs. Herman Lukow & Jeffrey Kreutzer

THE VIRGINIA TBIMS TEAM

EDITOR

Matthew Wetsel, B.S.

PRINCIPAL INVESTIGATOR AND PROJECT DIRECTOR—RESILIENCE RESEARCH

Jeffrey Kreutzer, Ph.D.

CO-PRINCIPAL INVESTIGATOR

David Cifu, M.D.

PROJECT COORDINATOR

Jenny Marwitz, M.A.

PROJECT DIRECTOR—COUPLES RESEARCH

Emilie Godwin, Ph.D.

MEDICAL DIRECTOR

William Walker, M.D.

BIOSTATISTICIAN

Adam Sima, Ph.D.

DISSEMINATION COORDINATOR

Kelli Gary, Ph.D.

PROGRAM EVALUATION

Jeong Han Kim, Ph.D.

RESEARCH ASSOCIATES

Matthew Wetsel, B.S.

Nancy Hsu, Psy.D.

Megan Edwards, M.P.H.

DIRECT CORRESPONDENCE TO:

Matthew Wetsel

P.O. Box 980542

Richmond, VA 23298-0542

(804) 828-3703

Email: wetselme@vcu.edu

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After brain injury (TBI), most caregivers are spouses, parents, or other family members of survivors. Research tells us that, as time passes, survivors rely more and more on their families for support. After hospital discharge, friends of the family tend to visit less often and many become scarce. Heavy reliance on caregivers over long periods of time leaves many feeling "burnt out" and wondering where to turn for help and support. Caregivers often feel alone as they deal with difficult emotions such as anger, worry, guilt, frustration, and hopelessness.

Researchers at Virginia Commonwealth University (VCU) Medical Center know that caregivers also need support. So, they studied the sources of support caregivers most often rely on. The researchers also collected information on the helpfulness of each source. Sharing this information will help caregivers select sources of support that are reported as most helpful by those with similar challenges. This information may also be helpful to clinicians and others who link caregivers with support resources.

The VCU research team collected information at six (contd pg.4)

Adjustment and Resilience Brain Injury Study

If you have had a TBI, you may qualify for a research study at VCU. We are evaluating the helpfulness of an outpatient rehabilitation program to help people adjust to having a brain injury. Qualified volunteers will participate in seven education sessions. Study volunteers will be given information on brain injury, local resources, skills development, and positive coping strategies. Topics will include setting goals, problem solving, managing emotions and stress, and communicating well.

If you are interested in participating and are 18 or older, please call Jenny Marwitz at 804-828-3704, or toll free at 1-866-296-6904, or by email at jhmarwit@vcu.edu.

Megan Edwards, MPH, is a psychometrist and research specialist in the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University. She currently conducts research and provides neuropsychological assessments to adults with TBI and other health concerns.

**HAVE YOU
MET MEGAN
EDWARDS, MPH?**



Megan grew up in Atlanta, GA and graduated in 2004 from the Rollins School of Public Health at Emory University and in 2002 from Emory College. She was a four year member of the varsity women's soccer and track teams and was the principal percussionist in the Emory Wind Symphony.

Megan has worked in research at VCU for almost ten years in a variety of departments including Psychology, Psychiatry, Healthcare Policy & Research, Cardiology, and Research Subjects Protection. Megan hopes to attend nursing school in the future and work as a Clinical Nurse Coordinator.

Outside of work, Megan enjoys spending time with her husband and 3 year old daughter, participating in Crossfit, and visiting friends and family in Atlanta.

Mark Your Calendar!



Richmond Support Group

- ♦ **Location:** 3rd Monday every month at 6 pm, Children's Hospital Auditorium, 2924 Brook Rd, Richmond, VA 23220
- ♦ **Contact:** Call the Richmond BIAV at 804-355-5748 for more info!

Richmond Aphasia Support Group

- ♦ **Location:** 2nd Thursday of every month from 6-7pm at the Weinstein JCC, 5403 Monument Ave, Richmond, VA 23230
- ♦ **Contact:** (804) 439-2657 or email at ricaphasia@yahoo.com

Hopewell Tri-Cities Support Group

- ♦ **Location:** 2nd Tuesday every month at 6:30 pm, Nelson Library 209 East Cawson St, Hopewell VA 23860
- ♦ **Contact:** Call Mary Wallace at 804-355-5748 or email at mary@biav.net

Chesterfield Support Group

- ♦ **Location:** 2nd Monday every month at 6:30pm at the Woodlake United Methodist Church, 15640 Hampton Park Drive, Chesterfield VA 23832
- ♦ **Contact:** Call Elizabeth Perry-Varner at 804-276-5761 or email eperryvarner@verizon.net

If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please call 828-3703 or email wetselme@vcu.edu.

Intervention for Couples After Brain Injury

Following the renewal of the TBI Model Systems grant at VCU, Drs. Kreutzer and Godwin have launched the Therapeutic Couples Intervention (TCI). The TCI is a continuation of our interest and commitment to family-focused research after brain injury.

Often, spouses or romantic partners take on a caregiving role when their partner suffers a brain injury. As such, the TCI is designed to assist couples after TBI. Topics covered in the TCI program include: communicating in relationships, managing stress effectively, establishing emotional intimacy, renewing physical intimacy, and more.

Participation is free, and study volunteers will be compensated for their time. If you are interested in participating, please contact Jenny Marwitz at 804-828-3704, or toll free at 1-866-296-6904. Or, send an email to jhmarwit@vcu.edu.



JUST FOR FUN!

US Presidents Word Find

It's the summer, so for Independence Day see if you can find the following US presidents in the word find above. Words can be forward, backward, diagonal, horizontal, and vertical. If you get stumped, answers are on page 7!



BUCHANAN
CLEVELAND
CLINTON
COOLIDGE
EISENHOWER

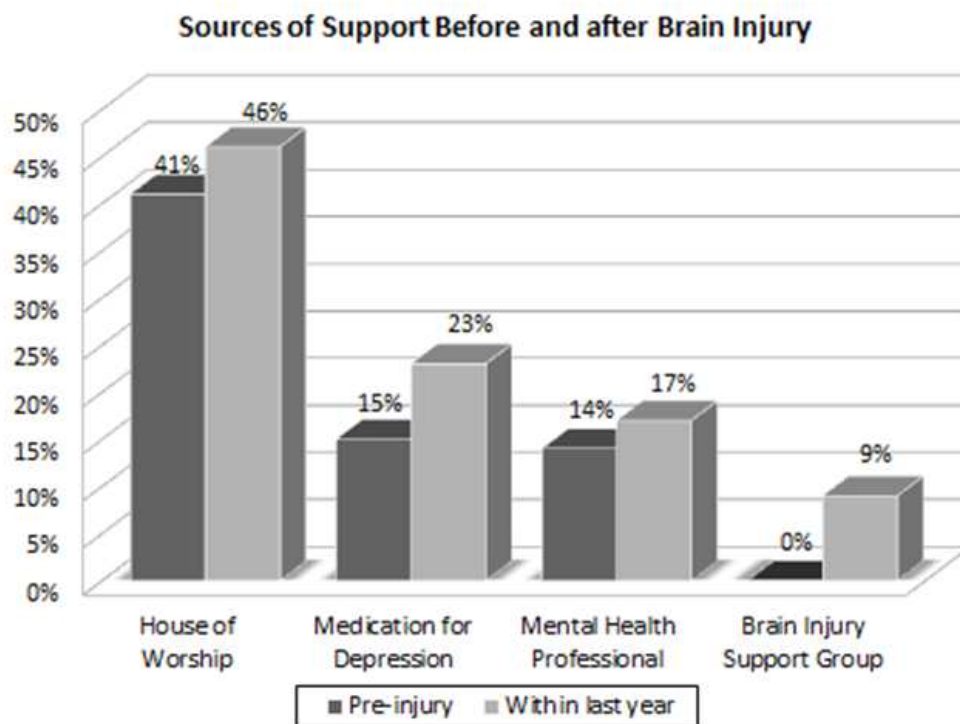
FILLMORE
HARRISON
JACKSON
JEFFERSON
JOHNSON

LINCOLN
MADISON
MCKINLEY
MONROE
REAGAN

ROOSEVELT
TAYLOR
TRUMAN
VAN BUREN
WASHINGTON

(*Caregiver*, contd. from pg.1) rehabilitation centers to learn about sources of support. Two-hundred seventy-three (273) caregivers for survivors of TBI completed a short questionnaire to identify the sources they used before the injury and within the last year. Time post injury varied from one to five years. Information about four commonly utilized sources was collected. The sources selected were a house of worship; a mental health professional (psychiatrist, psychologist, or counselor); medication to treat depression; and brain injury support groups. The helpfulness of each source was measured by asking caregivers to rate each on a scale ranging from one (not at all helpful) to five (very helpful).

Caregiver responses on the questionnaires were examined. The most popular source of support was a house of worship, used both before and after injury. Using medications for depression was the second most used source followed by seeing a mental health professional and, lastly, attending brain injury support groups. The chart below shows that caregivers reported using each source at a higher rate post- compared to pre-injury.



Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you'd like to share? If so, then we'd like to hear it, and it might get into a future issue of TBI Today!

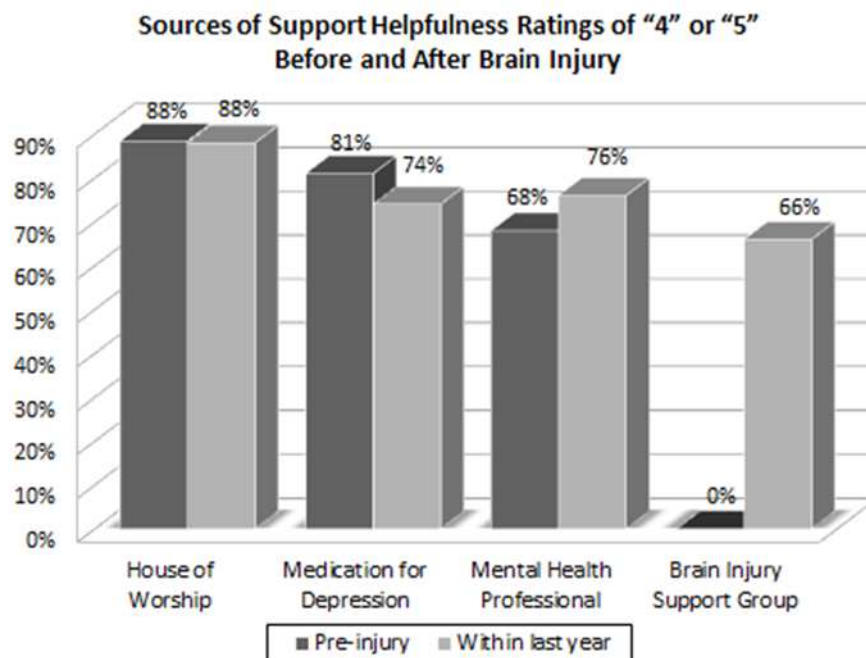
Submit to: jhmarwit@vcu.edu

or

TBI Today, VCU P.O. Box 980542
Richmond, VA 23298-0542



The next chart (below) shows the percentages of caregivers that rated each source as a four or five out of five in helpfulness on the questionnaire's five-point scale. The house of worship was the source rated as the most helpful both pre-injury and in the past year by the largest percentage of caregivers. The second largest percentage of caregivers rated medications for depression as helpful before injury followed by seeing a mental health professional as the third most helpful. Within the last year about three out of four caregivers rated both seeing a mental health professional and medications for depression as helpful. Brain injury support groups were rated as helpful by two out of three caregivers that used them.



The charts above highlight a number of issues that may be of interest to caregivers. Unsurprisingly, caregivers use all sources of support at higher rates after injury than they did before injury. However, it appears that medications were seen as less helpful after injury than before injury. This could be due to caregivers developing better coping skills as time passes. This idea would seem to be supported by the increase in the use and helpfulness of mental health professionals.

Since past research that shows that medications and counseling are equally effective for treating depression, this may be encouraging to those who are concerned about long term use of medications. The popularity and helpfulness of the house of worship may also be encouraging to caregivers who may have questioned their faith or otherwise lost touch with their faith community. Finally, although 66% of caregivers rated brain injury support (contd on pg. 6)

groups as helpful, less than one in ten caregivers relied on a group. This low percentage of use is a bit surprising since support groups are widely available and many caregivers express a desire to talk to other caregivers.

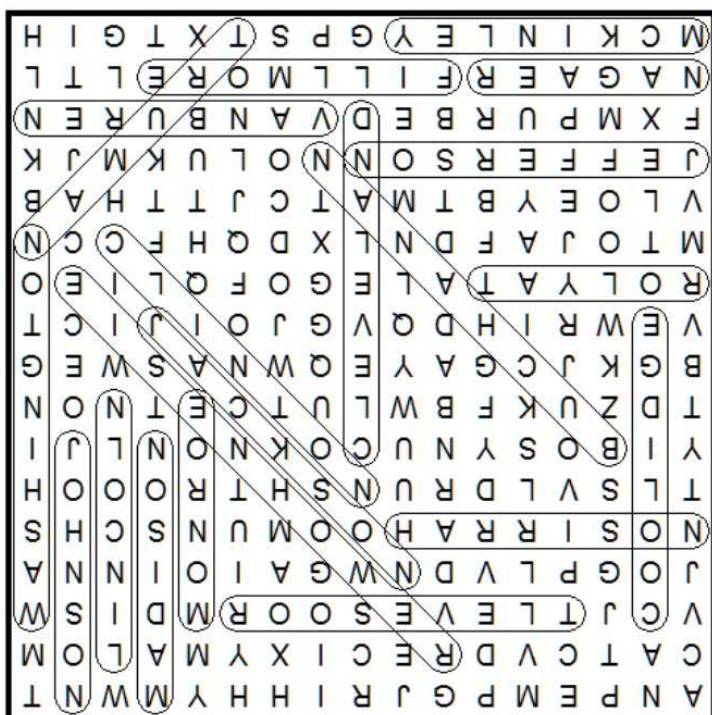
A note of caution; there are a number of limitations to this study that need to be highlighted. Apparently, caregivers rely on different sources of support as time passes. The present investigation did not look at each person at each time interval, drawing conclusions about individual change is difficult. Another limitation is that only a small group of support sources was examined. Very likely, caregivers rely on a wider variety of sources for support than the four that were included on the questionnaire. Further, although the house of worship was reported as most used and helpful, this study did not look at the specific type of support (programs, spiritual connection, etc.) provided. There may also have been hesitancy to report using a mental health professional or medications since some people are embarrassed about receiving treatment for mental health issues.

We have much yet to learn about the support needs of caregivers for survivors of TBI. In order to paint a more complete and useful picture, additional studies are required. The limitations to the current study outlined above can be resolved in the future in a number of ways. For example, gathering data from the same caregivers at different points in recovery would allow for the construction of typical support profiles by length of injury. This would inform caregivers and professionals alike on which services are most important to access at different points in recovery. We could also find out more about the variety of the sources used by conducting focus groups of caregivers to identify more classes and types of support they've used. Possibly, many other sources are used, such as pets or fraternal organizations, that could be included in revised questionnaires.

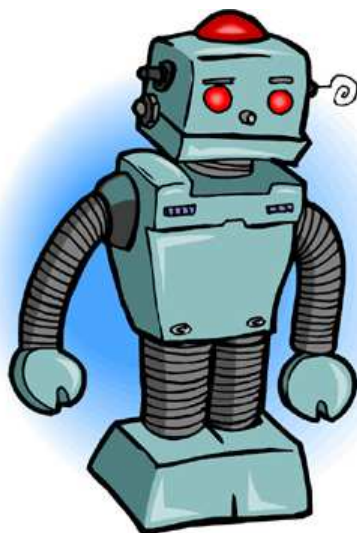
A final consideration for future studies would be to ask caregivers if they attended a brain injury support group but decided not to continue attending. Capturing reasons such as the format, location, time, or leadership would be of great use to professionals who plan, organize, and conduct these groups.

Caregivers for survivors of TBI need support just as survivors do. We know that as time passes survivors rely more on their caregivers for support. We don't have a clear

(contd) picture of where caregivers turn for their support or what the most effective supports are though. This study was a first attempt at answering these questions. From the information collected, attending a house of worship appears to be the most used and valued source of support. However, brain injury support groups look to be quite helpful but underutilized. Future studies are needed to broaden our understanding of caregiver sources of support so that individuals are aware of the most useful supports available and used. With a better understanding of supports used by caregivers, TBI rehabilitation professionals will also be better prepared to link clients with the most effective and efficient sources of support.



**Here are the answers for the word search on page 3.
How did you do?**



Did you Know? You can subscribe to *TBI Today* by email and get every issue sent directly to your computer, tablet, phone, or any other device that supports PDF. Best of all, it's free! Go to <http://model.tbincrc.com> and look for 'Join Our Mailing List' on the lower right. We also have back issues available.

In addition to the newsletter, the website is host to a variety of materials and fact sheets about recovery from brain injury which you can download for free!

We gave Pat a break for the summer so we could report on caregiver support. Have no fear, Pat and the Frequently Asked Questions will return next issue. In the meantime, if you have any questions for either column, contact information is below!



**Questions for Pat or the FAQ column are welcomed.
Send them to: "ASK PAT" OR "FAQ"
P.O. BOX 980542. RICHMOND, VA 23298-0542
or e-mail: jhmarwit@vcu.edu**



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Founded in 1983 by families and concerned professionals, the Brain Injury Association of Virginia is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them. Over 10,000 people find help from BIAV each year.

BIAV is a chartered state affiliate of the Brain Injury Association of America and exists to be the voice of brain injury through help, hope and healing for Virginians with brain injury and their families. We educate human service professionals and the community on the risks and impact of brain injury and advocate for improved medical and community-based services. Many of our staff members are Certified Brain Injury Specialists (CBIS Certified).

To find out more information about BIAV, contact us at 1-800-444-6443 or 804-355-5748. Or visit our website at www.biav.net.



The Voice of Brain Injury: *Help, Hope & Healing*