

Model System Updates

April 2018 Volume 16, Issue 1



Letter from the Director

By: Jeanne Hoffman, PhD

Dear Friends,

When our last newsletter went to press, we had just received the exciting news that the UW TBI Model System (TBIMS) received funding for another five years. As part of this funding, we will be able to launch new studies that we believe will have a significant impact on quality of life after TBI and help us better understand the course of recovery.

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TBI Care is our site-specific project for the 2017-2022 grant cycle. This study will address chronic pain, a common condition after TBI. Chronic pain is often complex and hard to treat. It also varies a lot from person to person. TBI Care will test a Collaborative Care model of treatment. A care manager will work closely with each patient over several weeks to coordinate and manage a pain treatment plan geared toward the patient's specific needs. This is an exciting undertaking as it has the potential to lead to improved practice guidelines and systems of care for treating pain after TBI.

The UW TBIMS team is leading a multisite study, called **Accelr8**, which will examine the impact of physical activity on recovery and function in persons with TBI. Participants will wear accelerometer devices that record activity and movement for specific periods of time. We will analyze these results along with data we already have in our Model System database to understand the relationship between the exercise people are actually getting and their symptoms, recovery, and overall wellness.

Our TBIMS is collaborating on two multi-site studies led by other Model Systems:

Cognitive Trajectories and TBI, led by Mount Sinai TBI Model System, will undertake an important examination of the factors affecting changes in cognition over time after TBI. We know that cognitive function improves in the first year or two after a TBI, but we know much less about cognitive change over the long term. Some people continue to improve, some stay the same, and some get worse. This study will help us to understand the course of cognitive function in the first 7 years after TBI so that in the future we may be able to develop strategies to reduce further decline.

We are also participating in the **Driving after TBI** study led by the University of Alabama TBI Model System. The goal of the study is to understand when people return to driving after TBI and the risks of returning to driving prematurely. This study will help us improve guidelines and protocols for determining when a person with TBI can safely start driving again.

Our TBIMS, along with five other TBIMS sites around the country, secured funding from the Patient-Centered Outcomes Research Institute (PCORI) for a new study called **BRITE**, for Brain Injury Rehabilitation Improving the Transition Experience. This study will compare the current approach to transition from the hospital to the community to a model based on what happens in the VA, to see which one leads to better recovery and quality of life.

You can read more about these studies starting on page 3 in this newsletter.

Finally, I would like to express my gratitude for the ongoing support from our community and the incredible team we have here at the UW TBI Model System. This grant cycle is very exciting and I anticipate many positive developments coming out of our work.

Jeanne Hoffman, PhD

Project Director, UW TBIMS

Announcements:

TBI State Conference

Tuesday, May 29 and Wednesday, May 30, 2018 Hotel Murano, Tacoma, Washington

"Forging New Pathways, Navigating New Dreams"

The 2018 TBI Conference brings together speakers, individuals with TBI, and caregivers for classes and sessions that are both informative and fun.

For information and to register, go to http://www.cvent.com/d/rtqp4y

What's Happening in TBI Research

TBI Care for Chronic Pain

The TBI Care study will test a new way of treating headache and other chronic pain in adults with TBI. Headache is one of the most common and disabling symptoms after TBI, with about a third of people reporting new or worse headaches a year after their injury. In addition, up to 73% of people with TBI report other types of physical pain that interfere with daily life and can affect recovery and long-term wellness. Because TBI-related pain is different for everyone and can be complicated by other conditions, a single approach to pain management does not work for everyone. The best treatment needs to be specific to each person, coordinated between their healthcare providers, flexible, and include a variety of medical and non-medical methods. In this study, we are using an approach called Collaborative Care. Collaborative Care uses a care manager who, with help from physicians and other providers, works with each patient to come up with treatments specific to his or her needs and circumstances. The care manager continues to work with each participant, in person or by phone, for 12 sessions over 4 months, and can adjust the treatment plan along the way as needed.

We will recruit participants with TBI and chronic pain who are patients at the Harborview or UW TBI rehabilitation clinics. Participants who enroll in the study will be randomly (like the toss of a coin) put into either the treatment group receiving the Collaborative Care approach, or the control group receiving the usual care. We will ask participants in both groups about their level of pain, mood, sleep and other details about their function at several time points following their enrollment in the study. By comparing responses between groups, we hope to learn whether the Collaborative Care approach is a better and more cost effective way to manage chronic pain in TBI.

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Several studies have shown Collaborative Care to be effective in treating chronic pain in people with other medical conditions, but this is the first one that involves people with TBI. We hope this study will result in improvements in the lives of individuals with TBI by reducing the impact of headache and other chronic pain on their day-to-day lives. This study is currently under review from our institutional review board and is not yet recruiting.

To learn more about this study, contact Laurie at (206-744-3607) or lpeabody@uw.edu.

Physical Activity and TBI: "Accelr8"

The purpose of this study is to learn more about the impact of physical activity on thinking skills, pain, sleep, depression, and overall quality of life in people with TBI over the first year post-injury. We know from past research that physical activity has been shown to improve specific health problems as



well as overall health and function. For people with chronic medical conditions such as TBI, things like exercise may be even more important for health, as well as independence, self-esteem, and satisfaction with life. The goal of this study is to get a basic understanding of how current levels of physical activity or inactivity are affecting people with TBI.

The UW TBI Model System is leading this multisite study, which includes three other Model System sites. We will recruit participants from inpatient rehabil-

itation, and before they leave the hospital, we will give them an activity monitoring watch to wear for seven days. They will wear it again at six and 12 months. We will collect and analyze data from the watches and from other sources such as phone interviews. Our hope is that the information we learn will help us to make recommendations for physical activity that can improve the lives of all people with TBI. This study is currently under review from our institutional review board and has not yet started recruiting.

Cognitive Trajectories and TBI

The Mount Sinai TBI Model System team is leading this study, which will look at patterns of cognitive function over time. Cognitive impairment is among the most devastating consequences of TBI and can also have a negative impact on mood and behavioral control. While cognitive function improves in the first year or two after a TBI, after that some people continue to improve, some stay the same, and some get worse. This study will examine cognitive function at different follow-up points after injury to see whether personal and other factors have an impact on cognitive function over time. These results may lead to new treatments that reduce further decline.

For this study we will recruit participants who are already enrolled in the TBI Model System study.

BRITE Study

The BRITE study, or <u>Brain</u> injury <u>Rehabilitation Improving the <u>Transition Experience</u>, will compare two different methods of transitioning patients from the hospital to outpatient care after a TBI. The goal of the study is to improve outcomes for patients and caregivers.</u>

Sometimes people who have had a TBI have a hard time returning to their usual activities after they are discharged from the hospital. We believe that the kind of treatment and services people receive after their discharge may affect how well people do over time. The main goal of this project is to learn more about how improving the transition from inpatient to outpatient care can result in better outcomes for patients with TBI, their families, and healthcare providers. We believe this research study will provide important information to help people with TBI and their caregivers in the future.

This is a multi-site study taking place at six US hospitals and led by the UW TBI team. At our site, we will recruit patients out of inpatient rehabilitation at Harborview Medical Center (HMC) and the University of Washington Medical Center (UWMC). Participants will be randomly assigned (like a coin toss) to one of two groups. One group will receive the usual discharge care, and the other will receive the usual care in addition to up to 12 calls from a TBI Care manager to review concerns and provide assistance to the family as needed. Participants in both groups will complete questionnaires four times during the study year. Findings from this study will help us identify TBI discharge services and guidelines that improve recovery and well-being in individuals with TBI.

This research is funded through a <u>Patient-Centered Outcomes Research Institute (PCORI)</u> Award (PCS-1604-35115).

Contact Taylor at (206) 685-8354 or email tobata@uw.edu for more information.

Driving after TBI

Led by the University of Alabama TBI Model System, this study will be used to improve our understanding of the factors that influence a safe return to driving after a TBI. Driving is an important goal for people with TBI and can improve social activity, employment opportunities, and satisfaction with life. Cognitive problems can present challenges, however, and we don't fully understand the level of recovery needed for a safe return to driving. In this study, we



will survey individuals who are already in our TBI Model System study and ask about driving practices, patterns, and incidents as well as a group of newly injured individuals and follow this group over the first 2 years post injury to see when they return to driving. The results of this study will give us more understanding of when driving is safe after a TBI. It will also help healthcare professionals to be more consistent in how and when they recommend that patients return to driving. This study is currently under review from our institutional review board and is not yet recruiting.

Recently Published Research Results

Patient perspectives on quality and access to healthcare after brain injury

By Kristen Dams-O'Connor, Alexandra Landau, Jeanne Hoffman & Jef St De Lor

People with brain injuries often have health problems that continue long after the injury, or even get worse as time goes on. Problems with mood, memory, sleep, pain, seizures, and mobility can continue to make everyday life difficult, and it can be challenging for people to get the health care they need to treat these problems.

To learn more about the specific challenges patients with TBI face when trying to get the right care, researchers from the UW and Mount Sinai TBI Model Systems invited people with TBI and their caregivers to focus group meetings to talk about their experiences with health care. The goal of the study was to better understand how providers and health care systems can improve care for their patients with TBI.

Participants reported these problems and barriers to getting the care they needed:

- 1. Patients didn't get the right information at the right time from the hospital or rehab provider.
- 2. Insurance would not pay for some of the health services they needed.
- 3. There were no TBI services or specialist in their area.
- 4. Thinking and memory problems made it difficult to remember medical appointments or understand treatment plans.
- 5. Health providers did not seem to know about TBI, understand their problems, or take the time needed to work with them.

Participants suggested these improvements:

- 1. Health providers need more knowledge and training about TBI, or at least an interest in learning about it, in order to provide the best care to the patient.
- 2. Health providers need to communicate better with each other and with their patients.
- 3. Health providers should take more time with patients and make sure patients understood the treatment plan and next steps.
- 4. Health providers should follow patients with TBI more closely and send reminders about appointments.

The researchers concluded with these recommendations:

- 1. Improve education for general practitioners so they understand the symptoms and health challenges common to patients with brain injuries.
- 2. Increase access to specialized brain injury providers.
- 3. Educate providers on the communication and self-management needs of patients with brain injuries.

This study was published in the journal BRAIN INJURY 2018, VOL. 32, NO. 4, pages 431–441.

Resources Highlight

Physical activity is good for everyone. For people with brain injuries, physical activity is often a key part of leading a healthy, fulfilling and independent life.

The <u>National Center on Health, Physical Activity and Disability (NCHPAD)</u> is a national resource on health and wellness for people with disabilities of all kinds. NCHPAD offers free information and videos on topics related to physical activity, fitness, recreation, sports, nutrition, disability and chronic health conditions. Whether you want to play tennis, swim, exercise at home without special equipment, eat healthier meals, or find a disability-friendly fitness center near you, NCHPAD lists resources all over the U.S. It also has information for health professionals, educators and caregivers.





BIAWA's Annual Walk, Run & Roll

Brain Injury Alliance Washington's (BIAWA) 8th annual *Walk, Run & Roll for Thought* took place on Sunday, April 22 at Green Lake in Seattle. It was a great success, and the UW TBIMS team was there in full color (purple, of course)!

The event raises funds to support BIAWA's programs helping brain injury survivors, caregivers and loved ones.

Visit their website to learn about BIAWA's Resources Center, Brain

Health & Wellness classes for survivors and families, trainings for health and education professionals, programs for youth with brain injuries, and much more.

Brain Injury Alliance of Washington



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Who's Who at UW



Jesse Fann, MD, MPH, is an investigator on the UW TBI Model System, a professor in the Department of Psychiatry and Behavioral Sciences and adjunct professor in the Departments of Rehabilitation Medicine and Epidemiology at the University of Washington.

Dr. Fann received his BS in Electrical Engineering from Stanford University, his MD

from Northwestern University, and his MPH in Epidemiology from the University of Washington. He completed his residency and research fellowship training at the University of Washington, where he was Chief Resident at the UW Medical Center. Dr. Fann is Director of Psychiatry and Psychology Services and the Integrated Psychosocial Oncology Program at the Seattle Cancer Care Alliance (SCCA) and Affiliate Investigator at Fred Hutchinson Cancer Research Center.

Dr. Fann has over 20 years of experience conducting trials to improve outcomes in persons with TBI and other medical conditions. His research interests have focused on developing cost-effective strategies to manage mental health issues in patients with neurological conditions such as traumatic brain injury, spinal cord injury and multiple sclerosis, as well as in patients with cancer. He is one of the investigators on the TBI Model System's site-specific project called "The Effectiveness of Collaborative Care versus Usual Care for Pain after Traumatic Brain Injury." He is also a coprincipal investigator with Jeanne Hoffman on a large PCORI grant studying the effectiveness of using enhanced transition care along with standard care after discharge from inpatient rehabilitation for moderate to severe TBI.

Dr. Fann is originally from Chicago and has been in Seattle since 1990. He enjoys playing music, traveling, swimming, and skiing with his wife and two boys.

The Washington Traumatic Brain Injury Resource Center

BIAWA is first and foremost a source of support for those affected by Brain Injury, and the Resource Center is a critical part of this.

Brain Injury Alliance of Washington: www.biawa.org/

BIAWA Support Center: www.biawa.org/getsupport.php















TBIMS Updates

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