

Model System Updates

Summer 2020 Volume 18



Resilience and Coping in the Time of COVID-19

Hello from the University of Washington Traumatic Brain Injury Model System!

We again send out a message of good health. Given we have now been going through this time of *COVID-19* for the last five months, we are focusing this issue of *TBI Updates* on *resilience* and *coping*. Our first article will discuss the first virtual BIAWA *Health and Wellness* class which focused on managing depression with Huiting Liu, PhD. In another, Silas James provides 10 (or 11!) tips to help make the most out of telehealth clinical appointments. Also we will provide an update on some of the research being done by the University of Washington TBI Model System, as well as an update from the BRITE study. And finally, you will read about the latest podcast from BIAWA interviewing our own Dr. Jeanne Hoffman. Thank you for reading!

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Managing Depression with Huiting Liu, PhD



Huiting Liu, PhD is a Licensed Clinical Psychologist and Senior Postdoctoral Fellow at UW Medical Center.

Dr. Huiting Liu was gracious enough to present for the Brain Injury Alliance of WA (BIAWA)'s first virtual Health and Wellness class. She shared her expertise on managing depression, and we wanted to provide some of the lessons learned for our readers.

It is common to hear or read things about what depression is or is not. Much of the information out there is incorrect and often stigmatizing. This misinformation may be confusing or even harmful for people experiencing depression and those around them.

Dr. Liu started off the class by helping us answer the question: **What is depression?**

- Depression is a serious medical condition that is physical as well as emotional.
- Depression is a very treatable. It is NOT just part of getting older, but may develop later in life.
- If you feel low for long periods of time, it may be depression.
- Being depressed does not necessarily mean that you cry all the time. It could look like irritability, lack of emotion, or losing interest in activities you usually enjoy.
- Depression may be chronic or re-occurring.



Around 15%-20% of people experience depression at some point in their life. It is the top cause of disability in American adults and frequently co-occurs with other disorders. A person may receive a diagnosis of depression if they experience at least five of the following symptoms "more than half the days" for 2 weeks or more:

- Low mood;
- Loss of interest or pleasure;
- Weight/appetite change;
- Sleep issues;
- Slowness or restlessness;
- Fatigue;
- Guilt or low self-worth;
- Trouble concentrating; and/or
- · Wanting to harm oneself.

Approximately 50% of people who have had a TBI experience depression in the first year after their injury.

This may occur for a number of reasons, including physical changes to the brain or brain chemistry, and difficulty adjusting to disability.

Talk therapy is an effective way to treat depression. One type is called cognitive behavioral therapy or CBT. Pharmaceuticals may also be helpful, or a combination of both.

Dr. Liu provided many useful strategies to try for alleviating some symptoms of depression. She also talked about different components of depression symptoms, including:

- Thoughts
- Feelings
- Behaviors
- Physical reactions

(Continued on next page)

Managing Depression, continued

These components are all linked to each other. By making a small change in one of the areas, you begin to affect change in the other areas.

One strategy is to take time to **reflect** on positive events. Share these reflections with someone, or write them down. Another strategy is to **challenge** your automatic assumptions by asking yourself: *Is* this thought helpful? Is there any evidence supporting the thought? What is a more helpful or balanced perspective?

Dr. Liu discussed how it may be helpful to focus on behaviors. Her strategies to do this are broken down into: **Track**, **Schedule**, and **Remind**.

Track your level of accomplishment, as well the pleasure you get from the things that make up your day. Schedule some activities that you like doing (i.e., take a walk, do yoga, or call a friend). Lastly, remind yourself of these things by keeping a list of things you like to do. When you are feeling down or not feeling motivated, you won't have to try and come up with something that makes you feel better, because you already have this list ready for you. Dr. Liu keeps a comfort box with her favorite things like Earl Grey tea, fuzzy socks, family photos and nice smelling lotion. She also has her list of activities close by to remind her to go for a short walk, pet her dog, or call a friend.

Another way to **remind** yourself of ways to feel better is to create "coping cards"; short, helpful thoughts and/or positive "self-statements" written on note cards. Some examples of coping card statements include:

"My feelings are like waves, they come and go" or "This too shall pass"

Or, you can list qualities you admire in yourself (*I* am funny, honest, generous, dependable...).

Dr. Liu also touched on the topic of coping with stress during the coronavirus pandemic. She suggested we keep to a routine. Keep a regular sleep and wake time, and schedule activities. Engage in social interactions by reaching out to friends by phone, Skype or Zoom. Talking to others may really help. Limit the time you spend reading the news to 20-30 minute chunks per day. Shift your focus from what you don't have or can't do, to what you do have or can do.

Dr. Liu suggests seeking professional help if you are having symptoms. They can talk with you and assess for depression and help you decide if you need additional treatment. If you have thoughts of wanting to harm yourself or others, contact emergency services.

If you have a loved one who is experiencing depression, listen to their experience and allow them to express their feelings. Help plan and engage in enjoyable activities with them. Also encourage them to discuss their symptoms with their care team.

Below are some of the questions and answers from the virtual class we wanted to share...



Q: Fatigue and trouble with sleeping are part of my TBI and I know that it is common with TBI. Can we relate this to symptoms of depression? **A:** Yes, TBI and depression have many overlapping symptoms and fatigue and sleep difficulties are symptoms of both conditions. Many people have some symptoms of depression without having the full disorder itself. A mental health professional can help assess if you have depression in addition to TBI.

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Managing Depression: Q&A

Q: Is it safe to say that even if you don't believe it at the time that going through the motion of positive thoughts and praise is helpful overall?

A: Absolutely. Part of the problem with depression is that people with this condition tend to have automatic negative beliefs about themselves, their future, and the world. So it's going to be difficult for someone with depression to fully believe in positive thoughts even if they say them/hear them. But it is still helpful to make positive self-statements because the goal is to gradually increase our belief in them over time. The more that you practice and say these things to yourself, and pay attention to the evidence supporting them, the easier it will become to believe in them.

Q: How much does physical exercise and the release of endorphins into the system help?

A: Physical exercise is excellent for helping manage depression. Certainly endorphins are released during exercise which can make us feel good. At the same time there are also other potential ways exercise is beneficial as well. For example, it can give us a sense of accomplishment and increase our self-esteem. It may improve our cardiovascular functioning which promotes brain health. It is a positive activity that can take our mind off things and motivate us to do more activities, etc. So physical exercise is very helpful for multiple reasons. The release of endorphins during exercise likely plays an important role in managing depression but we're not sure to what degree it's due to that reason versus others.

Q: Do you have any resources for physical activities that can be done by people with limited mobility?

A: <u>Here</u> is a helpful website from the CDC with links to great resources. I would also recommend double checking with your doctor about activities

that are appropriate for your specific situation.

Q: I really needed this and will implement the strategies, but what do you do on days when you cannot leave your house?

A: I'm so glad you were able to make the time to join the class today. I recommend starting small and implementing just one strategy each week. Is there one self-care task you can focus on this week? As we start to establish a new routine, we can slowly add more strategies or activities in. Slow down and build your confidence through reaching a small goal first. Then work back up to your goal. If it's hard to make yourself exercise, consider joining a yoga, dance, or workout class. Having the structure and support of the group can help get us started.



OTHER RESOURCES:

Brain Injury Alliance of Washington (BIAWA)

Anxiety and Depression Association of America (ADAA)

Crisis Connections

24-Hr Crisis Line: 866-427-4747



Update on Research Studies



UW TBI Model System

The UW TBI Model System (UW TBIMS) study has 16 participating centers across the country that research long-term outcomes after a TBI. The UW **TBIMS** has been recruiting participants for this research for more than 20 years. In addition to interviews completed in the hospital, TBIMS participants complete follow-up interviews at one, two, and five years from their injury, and every five years thereafter. At UW, we currently have enrolled 1,229 participants, and have completed 3,523 follow-up interviews! We work very hard to complete as many follow-ups as we can, and our follow-up rates reflect that work with over 90% of follow-up calls completed at all time points. We are currently funded until 2022, and will re-apply for another five years of funding in 2022.

Trajectories of Cognition after TBI

The Mount Sinai TBI Model System team is leading this study, which looks at patterns of cognitive function over time in participants enrolled in TBIMS. UW is one of the sites recruiting participants and collecting data for this project. Enrollment has been completed, but those enrolled will still be asked to complete some tests at two time points between regularly scheduled follow-up calls

TBI Care

The TBI Care study is testing a new way of treating headache and other chronic pain in adults with TBI using an approach called collaborative care. We began recruitment in 2018, and aim to complete the study in 2022. Currently, we have enrolled 114 out of our overall goal of 158 participants. We enroll people from the UW and Harborview Medical Center TBI Clinics, and have been thrilled with the high level of commitment from our participants. So far, we have been able to complete 96% of our planned follow ups.

ACCELR8

The ACCELR8 study aims to learn more about the impact of physical activity on the recovery after a TBI in areas like thinking skills, sleep, depression, and overall quality of life. UW is the lead site of this multi-site study that enrolls participants during their hospital stay and follows them for the first year after their injury. Participants wear an activity tracking device (Actigraph) a few times after leaving the hospital, as well as complete phone interviews. Current enrollment numbers are 129 participants for all sites, with 40 of those participants enrolled at UW. Follow up rates are about 80% across all sites. We will

complete enrollment in June of 2021.

Update on Research Studies, Continued

Return to 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. We enrolled 40 subjects at one of their TBIMS follow ups and another 40 participants will be asked driving questions at injury, at 1 and 2 year to better understand when people return to driving and the factors associated with a safe return to driving.

Brain Injury Rehabilitation Improving the Transition Experience (BRITE)

The BRITE study compares two different methods of transitioning patients from the hospital to outpatient care after a TBI. A multisite study led by UW, the goal of the study is to improve outcomes for patients and caregivers. Current enrollment across all sites is 607 participants and 375 caregivers. Of that, UW has enrolled 105 participants and 62 caregivers. For follow ups, UW has completed 390 and missed 28. The BRITE study started the fourth year in August, 2020.

TBI and Chronic Pain

With the goal of enrolling 3,800 participants who are being followed in TBIMS, this substudy aims to better understand chronic pain following TBI. This study is unique in that it can be completed by participants online using a web survey, through the mail, or by an interview on the phone. Thus far the UW has completed data collection on 207 participants.



Late Effects of TBI (LE-TBI 2)

LE-TBI 2 aims to learn more about the long-term impact of moderate to severe TBIs and involves brain tissue donation if the subject should pass away during the course of the study. With the original goal to begin visits in February 2020, the impact of COVID-19 has put the study on hold until in-person testing and MRI scanning resume.

Ten Tips for Telehealth By Silas James

Today with COVID-19 and the need for social distancing, both health services providers and consumers are working to be safer. Insurance has expanded the types of care you can get remotely. As a result, many of us find ourselves having our first telehealth appointments. Today you probably have more options for access to care, with less traveling and likely less fatigue. But with any new uses of technology there will undoubtedly be some learning and mistakes, and telehealth is no exception! Below I've compiled a list of ten tips to help you have the best of all possible telehealth visits:



1. Treat it like a regular appointment, it is!

- Minimize distractions: close other apps that might distract! You wouldn't check your email
 during an in person appointment. The same goes for other types of distractions, if you live
 with other people let them know that you'll be busy during your appointment. Close the
 door, if possible.
- Dress appropriately: if you would normally move around during an appointment, assume that you'll be doing that during the telehealth appointment

2. Sign up to be able to access your digital health record.

 If your provider uses a digital chart, make sure that yours is set up and all your information is current. This is how your provider will get follow up information too you. Also having all your medications listed in the same place can help protect against negative drug interactions.

3. Ask what equipment to use.

- Either a computer or phone will work for most things. In general, a cell or mobile phone will give you more flexibility because they're smaller so you can move them easily and put them anywhere. The smaller screen, however, could be less than ideal if your appointment is mostly a conversation. Using wireless headphones with either a phone or a computer could be helpful if you're going to be up and moving around.
- Some questions you can ask to help you decide: Will I need to move the camera around? Will I be getting up and doing things? Are we going to look at documents? Will my provider be sharing their desktop?

4. Do your paperwork before you check-in.

 We've all been guilty of going to appointments without completing all the paperwork. For telehealth appointments it's even more important to have it done ahead of time. Finish your paperwork ahead of your appointment so that you can get the most out of your appointment.

Ten Tips for Telehealth, continued

5. Sign in early.

- Depending on the services your provider uses for telehealth there may be a few screens of information to review or update before you get to the visit. Some telehealth software will want to confirm it's you but sending you an email, text message, or calling you.
- For your first few appointments, just assume that you'll need a little time for trouble shooting: you may need to adjust settings on your computer or phone, maybe even restart the program or your device. All this can take time.

6. Test your equipment before your appointment.

Most telehealth software has a feature that will let you test your audio and video before
going live. If you're using a new service, new device, or new provider it's a good idea to do a
dry run before your appointment. This can help you identify any potential trouble before
your appointment.

7. Have a backup plan.

• Things happen, computers crash and Wi-Fi drops out. If you have multiple devices that work for telehealth, it might be a good idea to have them nearby with software installed in case the unexpected happens.

8. Speak up to address any communication gaps!

• Even if you don't notice it, our bodies do a lot of communication we don't realize how much we take nonverbal communication for granted until it becomes limited. When you're planning what you want to talk about, it can also help to note how these things effect you or emotions you have around them, this will help you be aware of why they're worth discussing an help you clarify anything that your provider might not be understanding.

9. Take advantage of your environment.

 Sometimes during appointments we may need to describe something that only happens at home. Maybe a certain spot on your hand hurts from playing the guitar, or you get headaches while you're working on the computer. If there's something that you can illustrate better since you're at home, do it!

10. Ask your pharmacy about delivery options.

- Many pharmacies offer delivery services, they might charge a few dollars for this but it could also be worth it to maintain social distancing.
- You can also call the pharmacy and give permission to someone else to pick up for you.

BONUS: Here's one more thing that could be helpful even for an in-person appointment.

11. Make a list of things that you want to address; this can help keep your appointment on track.



The TBI Care Study

Interested in participating in research?

We are looking for volunteers to participate in a study called <u>TBI Care</u>. This study compares a treatment for pain using an approach called collaborative care with the usual care approach. Collaborative care includes a care manager who works directly with a patient as well as their physician and an expert team of providers to coordinate medical care and deliver behavioral interventions that are personalized for each patient. This approach not only focuses on treatment of pain, but also addresses some of the common co-occurring problems that often happen when people have pain including difficulties with mood, anxiety and sleep.

Study participation lasts for six months and can take place by phone, video calls, or in person.

You may be eligible to participate if you:

- Have had a mild-to-severe TBI more than 6 months ago
- Experience pain (including headache and/or other kinds of pain) in the past 6 months
- Receive your care from a TBI physician at either Harborview or UW Medical Center Rehabilitation clinics

Participants are randomly assigned (like a coin toss) to either the treatment group or the group receiving usual care. There is a compensation of \$50.

For more information contact

Laurie Peabody by phone at 206-744-3607 or

lpeabody@uw.edu

ClinicalTrials.gov Identifier: NCT03523923



All studies are voluntary and will not affect the care you receive at the University of Washington.

In the Community



In the 5th episode of the BIAWA podcast *Brain Injury Today*, host Deborah Crawley, BIAWA Executive Director, has a conversation with our own Jeanne Hoffman, PhD Director of the UW's TBI Model Systems to discuss how research is helping improve outcomes for people with traumatic brain injury.

BIAWA offers helpful information and resources as well as comfort and strategies to get through this time of isolation and uncertainty. The BIAWA also has a **Resource Line** Monday thru Friday where you can connect with staff.

BIAWA Resource Line 877-982-4292



BIAWA Podcast: Brain Injury Today

- Ep. 5: From Research to Reality: Improving outcomes for people with traumatic brain injury.
 LISTEN HERE
- Ep. 6: I'm a miracle: How ex-Husky Darin Harris has learned to live with his traumatic brain injury.
 LISTEN HERE

We will get through this together!

BIAWA Walk, Run & Roll

The 2020 Brain Injury Alliance of Washington's 10th annual Walk, Run & Roll took place 100% virtually on June 20th. Participants Walked, Ran or Rolled in their neighborhood, on their favorite trail or even on their treadmill at home - from anywhere in the world!

The UW TBI Model System team participated virtually to help raise money to improve the lives of people who have had a brain injury, their loved ones and caregivers with free Brain Health and Wellness classes, support groups, speakers, research and more.

Find out about the BIAWA at www.biawa.org



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Who's Who?



Meghan Gill joined the TBIMS research team in November of 2019 as a research assistant for the Late Effects of Traumatic Brain Injury (LE-TBI) study. While the majority of her responsibilities revolve around recruiting and meeting with LE-TBI study participants, she has also been helping out on other studies such as TBI Care while inperson visits are suspended due to COVID-19.

A recent graduate of the University of Washington, Bothell, Meghan received her BA in Community Psychology and minor in Neuroscience, combining her curiosity for understanding both biological and social aspects of the brain. In college, Meghan was a research assistant for a psychology professor studying the psychology of racism and anti-racist movements. This research ignited her passion for social justice and for the detail-oriented work required for gathering data. In the last summer of her under graduate education she had the opportunity to study abroad in Chile learning about their healthcare system. Truly intending to be a life-long Husky, Meghan's long-term goal is to return to UW to pursue a PhD in Neuroscience. She hopes to eventually head research finding cures for complex neurological and psychological diseases.

Born and raised in the Seattle area, Meghan admires the natural beauty in this region. One of her favorite things to do is to hike the many trails and photograph the breathtaking views, but when not outdoors, she enjoys spending time with her friends, playing violin, and listening to audiobooks.



The Washington Traumatic Brain Injury Resource Center

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

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

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















TBIMS Updates

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The contents of this newsletter were developed under a grant from the <u>National Institute on Disability</u>, <u>Independent Living</u>, <u>and Rehabilitation Research</u> (NIDILRR grant number 90DPTB0008). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).















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