



Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury (DCoE) Webinar Series

October 8, 2015, 1-2:30 p.m. (ET)

“Effects of Chronic Mild Traumatic Brain Injury: Caregiver Perspectives and Knowledge Gaps”

Welcome and thank you for standing by. All participants will be on listen-only mode until -- excuse me -- the listen-only mode for the duration of today's conference. This conference is being recorded. If you have any objections, you may disconnect at this time. I will now turn the conference over to Elizabeth Pletcher. Thank you, and please begin.

Thank you. Good day and thank you for joining us today for the DCoE Traumatic Brain Injury August Webinar, "Effects of Chronic Mild TBI: Caregiver Perspectives and Knowledge Gaps." My name is Elizabeth Pletcher and I'm a Recovery Support Specialist at Walter Reed National Military Medical Center as Contract Support for the Defense and Veterans Brain Injury Center. I will be your moderator for today's presentation. Before we begin, let us review some webinar details. If you experience any technical difficulties, please visit dcoe.mil/webinars to access troubleshooting tips. Please feel free to identify yourself to other attendees via the chat box, but restrain from marketing your organization or product.

Today's presentation references resources and continuing education. Accreditation statement are available for download from the "Files" pod and will archived in the "Online Education" section of the DVBIC website. This continuing education activity is provided through collaboration between DCoE and Professional Education Services Group. If you preregistered for this webinar and want to obtain a CE certification or certificate of attendance you must complete the online CE post-test and evaluation. Please note, registration is required for each webinar, regardless if the participant has an existing PESG account. After the webinar please visit dcoe.cds.pesgce.com to complete the online CE evaluation and post-test, and to obtain your CE certification or certificate of attendance. The evaluation will be open through Thursday, October 22nd, 2015.

Throughout the webinar you are welcome to submit technical or content-related questions via the Q&A pod located on the screen. All questions will be anonymous. Please do not submit technical or content-related questions via the chat pod. I will now move on today's webinar, "Effects of Chronic Mild TBI: Caregiver Perspectives and Knowledge Gaps."

Family caregivers of service members that experience chronic effects of mild traumatic brain injury discern that their loved ones experience a myriad of cognitive, emotional, and behavioral problems. Caregivers often experience many of these same issues, disrupting the family dynamic. They often feel marginalized by the medical system and conclude that their health care providers lack insight into their experiences. Knowledge gaps also exist regarding what caregivers understand about mild TBI and resources to help them manage symptoms and patient outcomes. This webinar will address these issues and explore how education for caregivers, family, friends, and health care providers could potentially enhance treatment outcomes and caregiver success.

At the conclusion of this webinar participants will be able to describe three primary issues that present as common themes among families dealing with chronic mild TBI; articulate how inclusion of the caregiver in the care continuum can lead to increased support for the chronic mild TBI patient; apply education as an intervention to reduce risk factors for persistent symptoms and negative outcomes.

Ms. Pam Sjolinder is the DVBIC Regional Education Coordinator at Intrepid Spirit One, National Intrepid Center of Excellence Satellite at Fort Belvoir in Fort Belvoir, Virginia. She facilitates the 12-week faith-based REBOOT Combat Recovery course, which addresses the spiritual wounds of war. Ms. Sjolinder has served as a life skills trainer in a residential rehabilitation facility, working with active duty service members, veterans, and their families dealing with TBI and posttraumatic stress disorder. She is a Certified Brain Injury Specialist and member of the Academy of Certified Brain Injury Specialists. Thank you for joining us today, Ms. Sjolinder.

Thank you, Elizabeth, for that introduction. So the views and opinions expressed in this presentation today are mine and do not represent the official policy of the Department of Defense, the United States Army, or of DVBIC. I do not intend to discuss the off-label/investigative use of commercial products or devices. And I have no relevant relationship to disclose.

I'm a trained educator with a specialization and certification in brain injury. And for the last seven years I've educated service members, veterans, caregivers, and family members on traumatic brain injury symptoms and behaviors. And to begin today we want to do a polling question just to see who is in our listening audience today. So go ahead and please check off which discipline is yours.

Okay, it looks like we have a little more of social works and case managers in our audience today. Welcome to all of you. I wanted to talk a little bit about the Case Series study that is the foundation for this presentation. So during these past several years common themes have persisted in my work with caregivers. Caregivers do not understand why their loved ones with traumatic brain injury behave the way they do and maybe say some of the things that they're saying. And I've consistently seen that the caregivers I've worked with over the years lack any real working knowledge of TBI symptoms and behaviors.

I was asked to gather some feedback by working with our caregiver support group at Fort Belvoir, Virginia. And we determined that a small case series would be effective in evaluating these issues. Fortunately, we already had caregiver spouses enrolled and receiving care in our program. So to begin this case series I developed a caregiver survey comprised of 22 questions that were structured in a logical pattern and ordered to query the caregiver's greatest issues.

So these questions centered around the caregivers themselves, their service member loved ones, their children. We wanted to learn about support, how much support were they receiving and who were they getting this support from? We wanted to learn about the intimacy issues that they're dealing with. Did they feel that they were included in the care continuum, and, if not, how were they feeling? We wanted to talk of issues of grief, ambiguous loss, loss of identity. We also wanted to find out what were the coping tools that caregivers used. What resources are they using and what do they look like? We also wanted to know what are the TBI facts that caregivers believe or what were the facts that they thought that they knew?

So going into this study we already knew that we'd probably find that caregiver spouses are deeply impacted by their loved one's injury. We also knew that exploratory studies would be needed to further understand some of these issues. And I want to emphasize that nearly everything that I am sharing with you today is from the caregiver's perspective. This is how the caregiver sees herself and her loved ones dealing with the symptoms and behaviors of TBI. All the caregivers in this case were female, married to a service member with mild TBI and persistent symptoms. And most of their injuries resulted from blast [inaudible].

So, going onto some of the caregiver survey questions, so the first questions I asked the caregivers is what was -- what is your perspective of the issues that your service member or loved one is dealing with? And you notice the three in red, this was 100% group consensus. So these were the three top issues that their service members loved ones were dealing with. So we're looking at a loss of identity. We're looking at issues of anger and this feeling of isolation that the service members have. They were also dealing with feelings of sadness, depression, blame, survivor's guilt, loss of interest, and the fear of the future.

We then asked the caregivers what was their perspective on the issues that their children were facing? The caregivers reported to me that their children had trouble understanding what was happening in the home and why behaviors were in the home. Children expressed fear. Some of their children felt that they were to blame for the issues in their home. Some of the older kids take on increased responsibilities. The caregivers reported that they saw role reversal in their children. In other words, the child became the parent, and the parent maybe became the child. Their children were sad. They felt isolated. And they had a sense of loss. They were missing, in this case, their dad. Some children are embarrassed by their injured parent's behavior and some children are fiercely protective of that injured parent. Their children expressed anger, defiance, and rebellion. And these issues became compounded when this child had a memory of that service member prior to their injury.

I asked the caregivers what are the issues that you're facing, and burned out is number one. And being burned out is typically a number one issue for any type of caregiver. But these caregivers have a long list of issues that they're dealing with. They're angry. They actually feel jealousy towards their loved one. They're getting all the attention and the caregiver is overwhelmed. They have issues of fear, loss, hatred, resentment, frustration. Caregivers feel misunderstood and lonely. They feel invisible to the people around them. They're missing that pre-injury spouse, longing for the past. They're walking on eggshells and they feel like they're always having to be the one to compromise. They feel unloved. They feel that they're no longer a wife. And they feel isolated.

I asked caregivers, "What are some of the issues that you're dealing with related to being a couple?" The two main issues are intimacy problems and this role reversal is coming in again. There's communication issues. They felt lonely, even as a couple. Caregiver's roles and duties become increased because they're picking up the slack many times for their service member loved one. They're angry, and that jealousy comes in again.

I asked the caregivers, "What are some of the issues that you're dealing with with friends and extended family members?" They said friends and families accuse the caregiver of being overprotective. Caregivers feel like friends and family don't understand what they're dealing with. They're unwilling to accept this new person and reframe that relationship in order to continue a relationship. Friends and family don't accept the gravity of the role of caregiver. Caregivers told me they hear these all the time, "It's in your head," "There's nothing wrong," "She should be better by now," "They're just faking it," "They should suck it up."

Caregivers feel very isolated from family and friends. They feel that family and friends are especially judgmental towards them when it comes to the medications that their loved ones are taking. And when outburst behaviors happen, friends and family become very judgmental and don't understand. They say to the caregiver, "You're wasting your life staying with him or her," "When are you going back to work," and "Why are you still with him or her." So friends and family would typically be your stronghold of support, but for many caregivers dealing with chronic mTBI, friends and families are encouraging them to end the relationship, "to get out of this."

I asked caregivers to share what are some of the issues that you're dealing with when you're dealing with providers in the medical care continuum. The main thing is they feel providers don't believe us. They say it's hard to get a diagnosis. Providers pass the buck. So they talk about their service member or loved one as kind of a hot potato in the care continuum. They move from provider to provider. Nobody wants to hold onto them too long. Caregivers feel that they're not listened to. They feel minimized and marginalized, which sometimes they feel is harmful for the patient. They feel rushed out the door. They believe that physical wounds take priority over invisible wounds. And they talk a lot about what they call "HIPPA violations," that they see gossiping, oversharing of patient information to the detriment of the patient. They feel that long-term treatment leads to familiarity, which in turn dilutes care and leads to inappropriate personal comments and advice.

We're now on slide 26. So what do caregivers fear the most? Well they feel the future just about more than anything. They fear for the safety of their loved ones. They fear retirement, dementia, regression in their treatment. One thing they fear is they call it their own "bad" behavior. Many of the caregivers that I work with admit to me that they are self-medicating, often like their service member loved ones. And

they're afraid that they're beginning to go down this path. They're afraid of being stuck in what they call this "hole" forever, with no support, alone against the world.

I asked the caregivers what did they feel were the greatest losses of their service member loved ones. The number one loss is that loss of identity. This feeling keeps coming through. They also have lost themselves, their pride. Many times they've lost their jobs. Service members feel like they've lost the respect of a lot of people in their unit. They've lost relationships because of their injury, and that male role is a big loss for service members. And, even though many service members don't acknowledge this, the caregivers say that there is a great sense of loss that they see on the part of the service member.

What do caregivers believe are the losses that their children are dealing with? They say that their kids have lost their moms or their dad. They've lost their childhood, their innocence, their independence. So sometimes they have to be home helping mom when normally they'd be out doing something else. Caregivers actually mourn that some of their children will never maybe know their real parent. And they're sad that their kids are not able to have only kid things on their minds.

So what are the caregivers' biggest losses? What do they feel that has impacted them more than anything else? Number one, they feel as if they have lost themselves. And this loss of intimacy is a very big issue for caregivers. They feel that they've lost their home, their career, their kids, their spouse, and their independence. Now, we know that they haven't physically lost that spouse, so we call this an "ambiguous loss." So this is when the person can be present physically but maybe not participating in family life.

So now we begin to see some common themes emerging. So service member patients are angry, isolated, and feel that they've lost who they are. Their children don't understand. They're fearful, sad, angry, and they feel isolated, and their childhood roles have changed. The caregiver is burned out, feeling lonely, isolated, angry, invisible, frustrated, and no longer a wife. And as a couple, loss of intimacy and role reversal are typically these issues. But family and friends don't understand; they're judgmental and they isolate that service member patient and caregiver from them.

Caregivers perceive that providers often don't believe them, making caregivers feel marginalized, minimized, unheard, essentially isolating the caregiver from the care continuum. So service member patients have lost their identity. Caregivers have lost themselves. And children have lost their childhood. So now we see these three common issues, the issues of anger, loss of identity, and isolation. If I were to have a fourth, that fourth common issue would be fear.

So moving onto slide 33. We typically think of isolation as the result of being physically separated from others. Isolation can also be the result of the perception of being removed from a community which causes this social or emotional aggravation. When a person experiences too much of this isolation or solitude, or feel isolated from others, they may develop feelings of loneliness, anxiety, helplessness, or depression.

So perceived isolation can lead to loneliness. It can also share the same meaning. So loneliness occurs when a member of or quality of relationships that we have is smaller than what we desire to have, or the intimacy that we desire is not being realized in that relationship. Loneliness can be separated into two types: emotional loneliness, which stems from the absence of an intimate figure, a partner, a best friend, this is that loss of intimacy that we see all the way through the spectrum; social loneliness, which stems from the absence of this broader group of contacts, this is the family and the friends and the medical care continuum. So this perceived social isolation and loneliness can lead to more chronic health conditions, depression, poor long-term health outcomes, and even early death and suicide.

So service members with TBI describe feeling lonely, even when they're surrounded by other people. This loneliness can result because of many reasons such as their difficulty talking with other people and understanding what they're saying, these are their cognitive deficits. Many survivors feel self-conscious after their injuries. They also worry about what others will think of them and they feel nervous being around other people. Many TBI survivors know that they're more irritable after their injury, so they tend to

pull back out of social situations. Fatigue and low energy are common problems. We all know [indiscernible] issues are prevalent in this demographic. Pain and other physical problems make it difficult for survivors to do the things that they were normally used to doing. Many are not able to drive. Most of us make friends through work or through social or recreational activities. And, again, family and friends feel uncomfortable often around a service member with traumatic brain injury.

So family members often feel isolated from one another. They also feel isolated from those around them who would normally be providing a means of support. So when everyone is feeling isolated from everyone, who is able to support whom in this situation? So after TBI, the caregiver often loses nearly all means of support. They love their loved ones' support. They lose family. They lose friends, children, and providers.

So what are some of the factors that might contribute to a lost support or this social isolation? Well, loss, in its many forms -- we've talked a lot about loss for all the family members. Poor physical health contributes to this isolation. Low morale, being a caregiver in itself contributes to social isolation. Geographic location; we know in the military, military families, every few years our PCS to a new location. So they're continually leaving support groups behind. Communication issues contribute to this, as well as transportation difficulties. So military families dealing with chronic mild traumatic brain injury typically have no control over these factors, that, unfortunately, puts them into a socially isolated environment.

Moving on to slide 40, here we have Table C-2, this is risk factors for persistent symptoms and/or poorer overall outcomes. This comes straight out of the VA DoD Evidence-Based Clinical Practice Guidelines for the Management of Concussion and Mild TBI. So you can see each phase of injury, pre-injury; peri-injury, which is at the time of injury; and post-injury, with the risk factors that should be assessed for persistent symptoms and poorer outcomes.

So notice on their peri-injury, at the time of injury, that a lack of support system is considered a Level C risk factor. This means that at least fair evidence was found that the intervention can improve health outcomes. Then take a look under post-injury, and post-injury is considered at least four to six weeks after the injury incident. Lack of support system appears again, and this time it's a Level A or Level B evidence, which means that at least fair evidence was found, that the intervention improved health outcomes, or good evidence was found that the intervention improved important health outcomes and that benefits substantially outweighed the harm.

So, according to the VA DoD Clinical Practice Guidelines it's recommended than an assessment of the patient with concussion mild TBI should include a detailed history regarding potential pre-injury, peri-injury, and post-injury risk factors for poorer outcomes. So we know at the peri- and post-injury phase new patients and chronic patients should be assessed for lower levels of or less available social support. Moving on to slide 42, the evidence statement for social support states that lower level of social support or higher level of psychosocial stress are risk factors for long-term post-concussive symptoms.

We're going to go ahead and do another polling question at this point. I'm curious to see how many of you, how many of your sites, are assessing for levels of support in your patients. Okay, good. It looks like there is some assessments that are happening in some of the clinics out there. Okay, moving on to slide 44.

Barriers to patient functioning can include the living environment, support systems, the patient's job, and finances. And so often we see with our TBI patients and families that not only is there a lack of support symptoms, many of the support systems that we do see negative support systems. So negative supports on the part of the spouse, family, or significant other can impair and even worsen functionality.

So why are caregivers sometimes not able to provide this positive support? So, taking a look at this slide, when caregivers walk into our clinic many of them are already feeling that they have lost everything. They're angry, fearful, mournful. I mean, the list goes on. They feel lonely, sad, isolated, lost, separated from all support. So if you are feeling like these caregivers are feeling, it would be very difficult to be the face of positive support for anybody.

So how might we modify these negative support systems? I believe that we can reduce these negative supports by educating the providers about the issues that caregivers are facing. This is what we're doing with you today. We can do it by finding ways to include caregivers in the care continuum and also by educating caregivers on symptoms and behaviors so that they, in turn, can educate families and friends. So including the caregiver in the care continuum may increase support for the service member.

So why is the caregiver often not involved in treatment? Number one, it is the service member's choice. Sometimes service members want to keep their symptoms hidden from their providers. Often it might be the provider's choice. Many times the logistics of a family will get in the way. There may be childcare issues. There might be transportation issues. And sometimes we do have families in crisis, so it would not be good for all of them together in one room.

So when I first start working with a caregiver I always ask them "What type of treatment is your service member loved one involved with?" Before their providers, what disciplines are they getting? And the answer is almost always the same, the caregiver is unaware of disciplines and the services that their service member loved one is receiving. So, much of the knowledge about their loved one's care is coming directly from the service member. Caregivers want to know more about the care that their loved ones are receiving. They want to help and support, but they are feeling left out. Caregivers believe that they can carry over some of the therapies into the home. And they believe that their input is very valuable for the care team to know.

So what are some of the benefits of including the caregiver and/or the family in the care continuum? Well, that caregiver knew that service member typically before the injury and they can verify any cognitive, physical, and behavioral changes. They're very aware of the symptoms that that service member is exhibiting and of all those behaviors. You know, they hear their loved one's unfiltered comments. So they hear many times what that service member does not share with a provider. They have an instinctive sense sometimes of what their loved one needs. They have history on the patient. And a really important one is that they're sometimes aware of symptoms when the service member is not aware of their own deficits. Another big one is caregivers are aware of medication reactions. Service members may choose not to report or they may forget to report medication reactions to their providers. So, giving the caregiver a sense of inclusion may help to move that caregiver from an adversarial or negative role to an advocacy role to be a force of positive support. And it serves to minimize the caregiver's negativity.

Moving on to slide 50. So what are some ways that we can include caregivers into the care continuum? Well we can educate providers on the issues that are facing caregivers and their children. Providers can sometimes encourage their patients to be open to having their loved one or their caregiver attend some of their medical appointments. We can develop ways to keep caregivers in the loop by having them attend some appointments. We can provide or develop educational resources for caregivers on treatments, symptoms, and behaviors. We can also keep the family informed of new research, new treatments, medical advances. Caregivers are very fearful of the future for their loved ones, and any piece of factual information that they can get about what the future holds for their loved one will serve to diminish some of those fears. And we can assure caregivers that their input is heard and valued.

So Andrew Sawyer, a caregiver for her husband who was diagnosed with TBI and PTSD, recently spoke at the American Legion Symposium this past June. She said "13 years into it, I need people to understand that not all injuries are visible and not all barriers to getting treatment are physical barriers. As a caregiver to a person that suffers memory loss, if the doctors don't talk to me, you get half the picture you need for treatment." So this caregiver perceives that without her input to the provider, her loved one actually experienced a barrier to care.

Education can be an intervention for increasing support for these chronic mTBI patients. So how can we decrease caregiver and family isolation, and increase patient support? Well we can do this by providing this TBI symptom and behavioral education to the caregiver and to the children in both the acute and chronic phases. We can teach caregivers how to teach TBI symptoms and behavioral education to family and friends. Caregivers want and need the support of family and friends, and with some of this knowledge

we can hopefully move family and friends into a more supportive role. And we can help this by offering support groups for caregiver participation.

Research shows that support groups can have a positive effect on social isolation if they have an implementation period of at least five months. From my experience, very few caregivers are able to fully participate in a support group for a full five months. They're often dealing with lack of child support, lack of transportation. Service members often need support [ph] out before that five months, or they're PCS'd or retired out to a new location. We all know that early education of patients and their families is the best available treatment for concussions, mild TBI, and for preventing/reducing the development persistent symptoms.

Okay, we are now on slide 56. So if the service member is past the acute stage now with persistent symptoms and the caregiver has not received any TBI symptom and behavioral education, an opportunity has now been created for that caregiver to begin to believe their own facts about TBI, which are often either partly true or not true at all. I asked our group of caregivers to tell me all the TBI facts that they knew. And, as you can see by these bullet points, they have very little, if any, hope for good outcomes. So caregivers believe that these are fact. And some of them are partly true. TBI is a life-changing event. If not resolved in six months, treatment is needed. We know that you need to get treatment before that six-month period. They believe that they're going to be dealing with this TBI for the rest of their life.

I was very surprised to learn that many caregivers believe that, without treatment, symptoms get worse and can lead to death. So there are caregivers out there that believe that if their loved ones hit their head another time that they could die from second impact syndrome. TBI and PTSD go hand-in-hand, causes behavioral issues, personality changes, intimacy disappears. So it's really important to educate caregivers on symptoms and expected outcomes after the injury. They need to know what symptoms are normal and expected and common for this period of recovery. They also need to be reassured about any expected positive recovery.

So, moving on to slide 57, I asked the caregivers, "What is it that you want to learn about TBI?" Well they want to know how to care for, what's the best care for the best outcomes? They're very vested in their loved ones getting better. They want to learn about adaptive technology. We teach service members about adaptive technology, so caregivers want to learn about that as well so that they can help their loved ones with it or support their loved ones in using these technologies. They want to learn about long-term outcomes. They hear about CTE, about early onset dementia. They want to learn how to live with TBI. They want to learn about long-term options, transitional care options, and community-based options. And, more than anything, they tell me they want to know how can they educate family and friends.

So lack of knowledge about long-term outcomes, I assume, creates a lot of fear. Many caregivers are asking me what does the future hold for me, what's going to happen when my loved one is 70 years old? There's a lot of fear around what does the future hold for us. I asked caregivers what is it you'd like to learn about caregiving. Well they want to know how to survive. They want to know how to accept what has happened in their lives. They want to know how to respond when others attack, and these others are family and friends who attack or negate the invisible wounds that their loved ones are dealing with. They want to learn how to regain, maintain, and continue intimacy. And a big item on their list is they want to know how to effectively communicate with you, with the providers. Each of the bullet points on these two slides could be topics of learning and discussion in support groups.

So moving on to slide 60. So here's a snapshot of the process used for caregiver education. Ideally, it would be great if we would screen new patients, their caregivers, families, for levels of isolation and loneliness, and then have them identified for specific education follow-up. You need to determine, is it better to work with the caregiver alone, the caregiver and their service member as a couple. Sometimes I work with caregivers and children, and sometimes I work with the whole family together. I review the notes, talk with the referring provider, kind of get a summary of what is this family dealing with, what are the symptoms that are being exhibited in the home. And then I'll pull resources that pertain to those diagnoses and known issues.

And I initially start off by getting the caregiver's perspective on the issues and behaviors that they're dealing with at home. And then I'll provide education on these specific symptoms and behaviors. And I typically end it with suggesting ways for them to apply their new TBI knowledge in helping them to understand and deal with the behaviors. So my goal every time is to move this caregiver, this family, from the adversarial role to becoming this advocate or a positive support for the patient.

So now to slide 61. On several occasions, I have done couples TBI education. So even though this slide is meant to be funny, I can tell you that this scenario has happened to me on several occasions. So I'll turn to the service member and say, "Do you have any problems with your memory?" Now, I already know before meeting with him that he does have memory issues. That service member will look at me and say, "No, I do not have any memory issues." And then I turn and I look at the caregiver, and I see this look of total annoyance, and typically the education goes downhill at this point. So I normally have much better success when the whole family is together, rather than doing education as a couple. So with a family, often the service member feels validated when they hear their behaviors explained to their loved ones and they see their loved ones are there wanting to learn and wanting to understand what that service member is dealing with.

So I'm going to give you a couple case studies. This is kind of a typical example of two different education sessions that I had. So case number one is a caregiver mother with two sons, aged 15 and 20, and they're all distressed that their service member dad or the husband has pulled away from the family. They don't understand why this normally very heavy-participating dad is not interested in doing anything with the family anymore. So the caregiver is worried about her children. The older son is trying to be the parent to the younger son, making up for the dad's absence. So here we see that role reversal, that identity change. The younger son is angry and sad; he needs his dad.

So I ask the younger son, "What was the biggest issue that he was dealing with?" And he said the family had a tradition of making family movies and watching them together on a Friday night about once a month. He was really hurt and angry that Dad had stopped showing any interest in doing this. So I knew the dad had cognitive issues that would make it nearly impossible for him to continue this family tradition. And I educated the family on the issues, the difficulty that Dad was dealing with, and how it might be very difficult for him to take videos and organize a family night. So this new knowledge helped the 15-year-old begin to understand that it wasn't that his dad didn't want to, he wasn't able to complete this project on his own any longer.

So I asked the 15-year-old to think of something that he might be able to do with this new knowledge and understanding. And this young boy decided that he was now going to take on the family night project himself and ask his dad to help him out in order to have dad feel included and valued as part of this family tradition. So this one hour of family education helped to begin to reduce some of the tensions that this family was dealing with.

Case number two. So in this case the caregiver was at her wits end dealing with a very small child and her husband's moods and behaviors. The caregiver felt that his behaviors and his lack of sleep were the most difficult issues that she was dealing with. And she did say that he was receiving sleep hygiene training as part of his rehab. So I stopped and I said, "Is there a TV? Is there a computer? Are there video games in your bedroom?" And, to my surprise, she said yes to all three. So, in this case, even though the service member was receiving sleep hygiene training, he was either unable to remember or unable to follow through on implementing the tools that he was learning. So for this education session I educated the caregiver and gave her several resources on proper sleep hygiene so that she can help her loved one implement some of the working tools and assist her husband in getting some much needed sleep.

So let's summarize by reviewing the potential benefits of caregiver education and inclusion in the care continuum. So we know research has shown that increased positive support for a service member with TBI can reduce the likelihood of persistent symptoms and increase the chance of better outcomes and functioning. When caregivers are given the facts about TBI they will likely feel more helpful about the future. If caregivers are part of the care continuum they may be able to provide more support for their service member loved one and assist them with treatment compliance. So caregivers, families, and

friends, empowered with knowledge and understanding of their loved one's TBI symptoms and behaviors may now be able to move from this adversarial or negative support to a more positive and productive role, hopefully leading to positive lifestyle changes.

So on slide 65, I wanted to take just a couple of minutes to go over some of the resources that I typically use when I'm educating caregivers. DVBIC Family Needs line is a resource that I always use, and I especially use "Taking Care of Yourself While Taking Care of Others," this is a booklet on coping techniques for caregivers and their families. If there are children involved I'll give them our booklet on talking with children about TBI. So this is full of communication techniques to help explain the effects of mild TBI to children. And then "Addressing Family Needs," this is a tool to assist families dealing with TBI.

Even though these resources are kind of geared more towards the service member, I give these to the caregivers as well. I'll hand out the "Signs and Symptoms of Concussion and Mild TBI." This identifies symptoms and provides coping and recovery tips. Most of the caregivers that I work with are dealing with this chronic mild TBI. So I'll give them "Help with Ongoing Symptoms," and this addresses why symptoms continue to persist. And then there are many instances where the service member also has the diagnosis of PTSD. So I give them the handout "Concussion/Mild TBI and Posttraumatic Stress Disorder," which explains those overlapping symptoms and the importance of seeking treatment for both.

I often use our Mild TBI Symptoms Management Factsheet. This covers behavior, personality, or mood changes; head injury dizziness; headaches and neck pain; healthy sleep; and memory issues. If you go to our DVBIC website there is a tab called "DVBIC Family and Friends." So this site helps you explore topics that offer help and advice for caregivers, families, and friends. One of my favorite resources is "After Deployment," which is a website and also an accompanying app called the "LifeArmor Mobile App." And each of these has about 17 different modules that some are TBI, PTSD, sleep issues, depression, anger, family and friendship, life stresses. So there's a wealth of information and there are libraries on the website that I will go and I'll print a lot of information for the caregiver based on the issues that their loved one is facing.

I work a lot with sleep. We know a lot of our service members with TBI are dealing with sleep issues. There's no reason why the caregiver shouldn't load this "Cognitive Behavioral Therapy for Insomnia" app on their phones as well. And this helps the patients adjust and maintain sleep routines, it has sleep journals, tools for creating new habits and relaxation techniques. So caregivers are very willing to work with this app and help their loved one keep track of their sleep and encourage relaxation when they're trying to sleep. I'll hand out the Warrior Sleep Kit, which is a great toolkit with information. It also has a sleep mask, ear plugs, and educational materials in it. The Concussion Coach Mobile App provides concussion assessment and management tools, as well as community-based resources and support. This is a wealth of information for caregivers to help them learn more about the issues that their loved one's dealing with.

I work a lot with children, so I always hand out these two websites, Military Kids Connect, which is an online community with age-graded resources. On Military Kids Connect there's a section called "Topics" which educates children about invisible injuries like concussion and TBIs, and the impact that these have on the entire family. I'll give them information on Military Families Near and Far. So this is the Sesame Street for military families. So there's information on all sorts of topics about military deployment, injuries, grief, and self-expression.

Two resources I am never without are the "Big Boss Brain" and the "Our Daddy is Invincible" books. These are books that I use almost on a daily basis. And often I'll put these books into the hands of the service member with TBI and say, "When you read to your kids at night, read these books to them and talk about the things that you're feeling. Help your kids to understand what are some of your symptoms, what are some of the behaviors that you're dealing with."

And last, the DVBIC TBI Recovery Support Program. So this is a free resource which provides medical and non-medical services for up to 24 months to service members, members of the National Guard, reserves, and vets, as well as family members and caregivers of whose loved ones have sustained a TBI.

The recovery support specialists will follow them for two years and tap them into resources wherever they are. So that's the end of my presentation. Thank you very much for joining us today.

Thank you so much, Pam, for your presentation. So much valuable information offered there, and I'm sure that the audience agrees. If any of you have any questions for our presenters, please submit them now via the Q&A pod located on the screen. This month's highlighted resource is the Defense and Veterans Brain Injury Center's A Head for the Future campaign. Since the year 2000, more than 320,000 service members have been diagnosed with TBI. The vast majority of TBIs are diagnosed in non-deployed settings, from causes such as motor vehicle collisions, falls, training incidents, and sports-related injuries. A Head for the Future is an initiative to raise awareness of the signs, symptoms, and treatment of TBI diagnosed in non-combat settings. A Head for the Future also educates service members, veterans, and their families about the importance of preventing brain injuries in garrisons. The military community can access A Head for the Future's website at dvbic.dcoe.mil/aheadforthefuture to get facts about TBI, what a TBI is, prevention tips, and where and how to get help for brain injury.

Additionally, service members, veterans, and their families can follow A Head for the Future on Twitter at twitter.com/ahfff, and also on DVVIC's Facebook page. You can learn more about the campaign, DVVIC, and TBIs. As the A Head for the Future initiative continues to grow, new resources will be available for the military community. Later this month, the website will expand to include four state-of-the-art factsheets and video testimonials from TBI champions, service members, and veterans telling their TBI stories of recovery and hope. DVVIC wants service members, veterans, and their loved ones to know that they have the power to prevent, recognize, and recover from TBI. Please check out A Head for the Future.

Okay, it is now time to answer questions from the audience. If you have not already done so, you may submit questions now via the Q&A pod, and we'll respond to as many questions as we have time. Pam, if you don't mind, I would like to ask a question or two. Have you actually been able to track or see any of the benefits of caregiver education increasing support for the service member with chronic mild TBI?

That's a good question, Elizabeth. I don't specifically track, but I have seen benefits. And I can give you an example. There was one day when I was called by the front desk and told that there was a service member patient that wanted to make an appointment with me for marriage counseling. So I explained I'm an educator and not a counselor, but I went up front anyway to meet with this service member. And we went into a quiet room and I explained that I'm an educator, and asked him what it was he was looking for. And he told me that he'd been talking to several of the other service members at our clinic that were coming for TBI care and they had told him that by my meeting with them that it had helped the relationships that they had with their caregivers, with their loved ones. So I said, "Well what is it that you would like me to do?" And this is a quote from that service member, he said, "I would, please, like you and ask you to teach my wife that I am really not the jerk that she thinks I am." So there were feelings that by getting this education that the service members felt as if their relationships were a little bit better now that their wife or their caregiver understood more of what they were dealing with.

Okay, great. Another question is can you give an example of how caregiver exclusion from the care continuum can be seen as a barrier to care?

Yes. Caregivers talk about this quite a bit. For instance, I was having an education session with a caregiver. And during this session with me asking her what are some of the things that you're dealing with, and she kept emphasizing how this loss of intimacy in their relationship was one of the main reasons that their relationship was falling apart. And later on when I debriefed the provider who had referred this caregiver to me we found out that the service member had never reported this to any of the providers that he was working with. So the service member was getting behavioral health counseling, they were trying to help this service member's relationship, but, again, the provider was working with missing information. So when you're sitting with a caregiver and educating them, it's a very non-threatening situation and they will tend to share a lot of information with you. So this information can be then kind of put back into the care team for them to better able help out that service members.

Wonderful. Another question that we got is what knowledge or interventions do caregivers believe will help them the most?

The one thing that caregivers have said to me over and over again is they want to learn as much as they can about TBI symptoms and behaviors so that they can go to their friends and to their extended family members and say, you know, "This is the reason why my husband is saying what he's saying, this is the reason his behavior is off the way they are." Caregivers really want support from their friends and family. And many caregivers feel as if friends and family isolate them. So I have had many caregivers ask for some sort of educational materials that is geared towards family and friends in order to turn them from the negative supports to a more positive support for that caregiver and family.

Okay, great. Another question that we had was specific to the family education sessions that you spoke about earlier. The person who submitted the question is just curious how often you're doing those sessions, how frequently you're doing them, how long they are. Is this something you're just doing at the beginning of treatment or is this something that you're revisiting a couple times throughout the course of their care, and what your recommendations would be for how frequently would do something like that?

Well, by the time I see the caregiver this family has been in and out of many different facilities, and in and out of the hands of several providers. So when I meet with them, often they have not had any TBI education. So I'll set up a meeting, and it's usually for an hour. Sometimes I'll go longer if they feel the need to go longer. But what I do is provide a lot of additional websites and a lot of additional resources. And I typically don't see a caregiver more than a couple times. And so what I'm doing is I'm pointing them in the direction of all the resources that are out there. Caregivers, you will find, does not have time to come in on a regular basis for education. So I try to pack as much as I can into those one or two sessions, and that truly is enough, because if they've got the tools in hand, they can start searching on their own. And I always make sure that they know they can call me or email me or come in to see me whenever they want.

Wonderful. Another question is what is the best support out there, in your opinion, for caregivers?

Well, right now, because of the lack of support that so many caregivers are dealing with, support groups are the best form of support. The caregivers that I talk with, that are actually involved in our caregiver support groups, are dreading the day that they have to leave. Many of them feel like they're being torn away from the only source of support that they have. So if we can overcome these obstacles of childcare and transportation issues, and we can provide support groups for caregivers for, you know, at least an extended period of time, this is a great means of support. Family and friends, again, caregivers really want and need the support of family and friends. But, as it stands right now, support groups are the one thing that is supporting them more than anything now.

Okay. And I think we have time for one more question. Are there any existing resources that you're aware of that teach caregivers and their service member how to re-establish or replace intimacy in their relationships? Do you have any recommendations for that or anywhere people can go for resources?

No, but that is one of the most asked resources that I get from caregivers. I'm not a counselor. I'm not a clinician. So I really don't have a resource for that. So I would say go to maybe a clinical social worker that you work with. Some of you may also be clinical social workers. So I had not found that resource, and that would be a great resource to be developed for these caregivers and families.

Great. So that's something that we can refer them back to their providers for and to make sure it's a topic that they're bringing up with their providers and discussing with them and making them aware of what they can then give them the resources they need. Well than you very much, Pam. Wonderful presentation. And thank you all for the questions that you submitted.

After the webinar, please visit dcoe.cds.pesgce.com to complete the online CE evaluation, and download or print your CE certificate or certificate of attendance. The online CE evaluation will be open until Thursday, October 22nd, 2015. To help us improve our future webinars we encourage you to complete

the feedback tool that will open in a separate browser on your computer. To access the presentation and resource list for this webinar you may download them from the "Files" pod on the screen or at the DVbic website, dvbic.dcoe.mil/onlineeducation. An audio recording and edited transcript of the closed captioning will be posted to that link in approximately one week. The chat function will remain open for an additional ten minutes after the conclusion of the webinar to permit attendees to continue to network with each other.

So next DCoE Psychological Health webinar topic, "Pharmacology in the Treatment of Behavioral Health Conditions," is scheduled for October 22nd, 2015, from 1:00 to 2:30 PM. The next DCoE Traumatic Brain Injury webinar, "ICD-10 Coding for Traumatic Brain Injury," is scheduled for November, the date and time is to be announced. Thank you all again for attending and have a wonderful day.