



Defense and Veterans Brain Injury Center “The TBI Family” Podcast
“Relationships and a First Season Review”
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Host: Dr. Scott Livingston

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Dr. Lilian Stephens: I think that the VA is very aware that any kind of injury or illness that impacts a veteran also kind of operates within the context of that veteran's family. And the family is very important for recovery and for treatment. And so the VA is trying to provide additional services and support for family members and caregivers.

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Dr. Scott Livingston: Hello and welcome to the TBI family. A podcast for caregivers of service members and veterans who've experienced traumatic brain injuries. This program is produced by the defense and veterans brain injury center, otherwise known as DVBIC and I'm your host, Dr. Scott Livingstone. In this final episode of this season of the podcast, we'll talk to caregivers about the podcast itself, whether they think podcasts are the best way to reach TBI caregivers and what more they'd like to hear about in possible future episodes. But first, a recent study looked at relationships in TBI's and came up with some data about which families are most likely to be destabilized by the injury. Dr. Lilian Stephens is a research psychologist at the hunter homes Maguire veterans affairs medical center in Richmond, Virginia. She's also the site principal investigator and database manager of the VA's polytrauma rehabilitation center, TBI model systems study. The TBI model system study is a study conducted at the VA's five polytrauma sites, where veterans who have sustained a traumatic brain injury are tracked over time in order to get the big picture about traumatic brain injury outcomes.

Stephens: So what we do is, when folks come to one of our five hospitals which have been designated as polytrauma rehabilitation centers, when they come to our hospital, if they're interested then they will consent to be a part of the study and at that point we try to gather as much information as we can about their brain injury. A very medical-- specific medical details. And then also try to understand where the individuals were in their life, in their situation or understand where people were in their life at the time of injury. So were they working? What was their relationship status? Any kind of medical history or mental health history, legal history. We try to get a big picture. And then we follow folks for a long time, so we try to follow up with people at one-year post injury, two years post-injury, five, ten, fifteen, twenty years post-injury. And again, at those time points, we're trying to get a really big picture about a wide variety of outcomes. So physical functioning, emotional functioning, employment, community participation and a lot of other kinds of factors. Again, medical history or changes in medical history or changes in mental health history. So that we can monitor and understand how folks recover after their brain injury.

Dr. Stephens and her fellow researchers looked at the relationship statuses of a group of veterans who'd sustained TBI. She spoke with TBI family producer, Terry Welch, and told him that while most relationships aren't negatively affected by TBI, those that are, generally share some common characteristics.

Terry Welch: Tell me a little bit first about the paper itself. What were you talking about? What were you interested in?

Stephens: So we were interested in looking at relationships stability after brain injuries. So we focused on those first two years after an injury and tried to see whether during those two years, folks changed their relationship status. So if they were married at the time of injury, did they stay married at that two year mark or did they have a change in their relationship. And then also, folks who were not married, who were maybe single, or divorced, or separated at the time of injury, did they also have a change at that-- over those two years.

Welch: This is part of larger series of studies correct?

Stephens: Yes. So this is definitely-- we consider this a first step in looking at relationships and the impact of traumatic brain injuries on caregivers and families. And then also, this is one of a series of papers that was bundled into a special issue in the Journal of Head Trauma Rehabilitation.

Welch: So what did you find in the study regarding relationship changes after TBI?

Stephens: So we found that the majority of folks had stable relationship status. So if we looked at the group of folks who were married at the time of injury, about 78% of them stayed married at two years post-injury. And then also, the folks who were single, divorced, or separated, we kind of put those together into one group thinking of them as folks who were not in a relationship. So those folks, also about 87% of them stayed in that same single, divorced, or separated category at two years. The other thing that we did was we tried to find factors that were associated with any change, right? So the folks who were married at the time of injury, 22% of them did change. So they had some kind of marital breakdown. And so we looked at different factors that maybe predicted that or were related to that change. And so, for that group, we found that folks who were younger at the time of injury, who had lower education level at the time of injury, and who had used mental health services prior to their traumatic brain injury were at risk for having more instability in their marriage. So at risk for more marital breakdown.

Welch: What do these findings tell you-- would be a way to move forward in the treatment of TBI?

Stephens: I guess one caveat would be that this is just one study so we would want to sort of try to do this again and see if we find the same things. But it does shed some light to the potential for being able to identify folks, early on, who might be at risk for marital breakdown. And so if providers at VA hospitals, sort of, notice that folks are coming in and they have these characteristics. We can't change how old someone is. We can't change their education level that easily. But we can use those things to, kind of, identify folks and potentially provide more education or provide marital therapy or couples counseling early on to try to prevent breakdown-- marital breakdown later on.

Welch: So that might be something to highlight for the case managers or someone like that.

Stephens: Definitely. Also psychologists on the unit, social workers. I guess the beauty of rehabilitation is that it's very interdisciplinary and so a lot of folks work with the patients and so it's kind of a group effort.

Welch: So what is this study though and the fact that the VA is looking at this? What does tell us about the VAs concern about the overall health and welfare of veterans?

Stephens: So I think that the VA is very aware that any kind of injury or illness that impacts a veteran also kind of operates within the context of that veteran's family. And the family is very important for recovery and for treatment. And so the VA is trying to provide additional services and support for family members and caregivers. So an example of that is the legislation that passed in 2010 that provided a comprehensive caregiver support program within the VA for caregivers of veterans. And that legislation was specific to post-9/11 veterans, but that opened up a wide range of services and financial benefits for caregivers.

I know that this is part of a larger series of studies. So what are the things you're looking at down the road? And is there is still room for other people to take part in these studies?

Stephens: So definitely. I mean, within the area of looking at family members and caregivers and relationship stability, there are a lot of other analyses or studies that we can do with our data to try to better understand these findings. So we were not able to look at things like the quality of a marriage, or how long people had been married, or whether the folks who were married had children. There are a lot of other factors that can lead to marital breakdown. And then also, one of the unique things about this study that we did was a lot of the literature has focused on that group of folks who had been married at the time of injury. And so we were also able to explore that other group, the single, divorced, or separated at time of injury. And we did find that there was only one factor that was associated with getting married at that two-year mark or being married by the two-year post-injury mark, and that was that folks who were injured during a deployment, compared to injured stateside, were more likely to be married at that two-year mark. That was a very interesting finding. There's not a lot of literature that we can go to to explain that, not a lot of people have looked at that, so we did a lot of speculation. But there may be two things that we thought might be related to that. So one is that it's possible that potential partners of someone with a brain injury might view having been injured during a deployment a little bit differently, and that may contribute to some sort of attitude or perception about recovery or what that injury might mean. Another thing that we speculated about was that it's possible that someone who had their brain injury during a deployment was more likely to be eligible and receive the benefits for the injury, therefore had more resources to recover and manage the consequences of the injury, and so may have in a better place to develop healthy relationships and enter into marriage. But that's an example of things that we would like to explore further down the line. And as we get more data and more information, we'll be able to kind of explore more avenues and kind of help fill in this picture that we're starting to get.

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Livingston: This is the 10th and final podcast of this TBI Family season. We hope that the podcast has been useful for you. In order to try to figure out if we've been doing the right thing here on the show, we've decided to reach out to a few caregivers and ask them to join us to get their takes on The TBI Family. Melissa Meadows and Emily Mather were willing to share their valuable time with us. They spoke with Terry Welch.

Welch: We started this podcast called The TBI Family in November of last year, and we had kind of three goals when we started this podcast. The first was to get information to caregivers tell them about VA programs, or non-profit programs, or DVBIC programs that they might be able to use to help make their lives easier, better, what have you. The other goals were to give them TBI information about ways to deal with symptoms or other sequelae we call them, that come up with traumatic brain injury. And, the third was to tell caregiver stories. We know from the Elizabeth Dole Foundation study they did with Rand that a large number of family caregivers feel like they're the only person going through a certain situation when we know that there's quite a few people going through this. So, we felt like a podcast would be the best way to reach people because it was on demand. So, you could listen to it on your own time at your own speed. And, we know you're busy. So, Emily do you think that what we've done with the podcast, whether you've listened to it or not, do you think a podcast is a good method to get information out to caregivers?

Emily Mather: I think that it's a really good method to get information out to caregivers because a lot of caregivers are very busy. And, they don't have the time necessary to dedicate to listen at a certain timeframe. They want to be able to do it at their own convenience.

Welch: And, Melissa, do you agree? Do you have some comments about that?

Melissa Meadows: I absolutely agree. Caregivers are very busy. And, having a moment to ourselves tends to be a little bit rare. So, having the ability to even just listen to something piecemeal to get the information, even if it's 2:00 in the morning that makes it doable. You just have to get the information out there.

Welch: So, some of the topics we've covered over the course of this first season that we're finishing up now, we're talking about it now. We've covered everything from a study on caregivers that we run. So, we're trying to get people to join that study. We've talked about the respite program for the VA. Our most recent one dealt with the VA stipend program that has been, at least the revocations, have been put on hold briefly. Do you think those are the sorts of topics that you as caregivers would like to hear more of? Or, are there specific topics that you

think, especially not just you, but the other folks that you talk about this, are there specific topics that you would like to hear more of from us? So, Melissa, I'll let you start on this one if you don't mind.

Meadows: The topics that you listed are key obviously, especially with the caregiver's stipend being so up and down in the years right now. So, there's a lot of concern with that. But, just the knowledge, a lot of caregivers don't even know that the caregiver's stipend is even an option. Or, that they should even apply for it. They don't think that they will qualify. So, having that information out there about the caregiver's stipend, how to apply for it. Who would qualify for it? What it entails. All of those things are extremely important. And, probably an individual podcast of that. And, that's for the respite care. I've been a VA caregiver now for a year and a half and I just heard about the respite program a couple of months ago. So, having a podcast on that is obviously also in my opinion essential. How to apply, qualify, what it entails, and that type of information. But, also a podcast on self-care. Just micro self-care even. Or, different places to find support. Or, different ways to get involved with other caregivers. Those are things that have really helped me as a caregiver survive, knowing where to find information and how to connect with others because, honestly, until I met other brain injury caregivers, I thought I was the only one. Because you said, who was going through my particular type of situation. I knew there was others out there worse. I mean, you see them on the news but I'd never met anybody. So I actually got to have-- I was on a retreat with other brain-injured caregivers and it was wonderful to find out that there were others going through-- not the exact same thing but similar situations and stories. And granted, some were a lot worse and some weren't as bad but we had a common meeting ground and it is so important to have a way to connect with other caregivers who can identify with what you're doing. And a podcast may be the only way that some caregivers have the opportunity to do so. So thank you for that.

Welch: So how about you, Emily. Do you have topics off the top of your head that you think you'd like to hear us cover and do you think we've-- from what you've heard-- so we have a good mix of the type of things that we're covering so far?

Mather: I do agree with Melissa. It's very important to educate on the caregiver program. There's a lot of information that people don't know. So I do really think that education piece is important. But it's also important to teach them that they're not defined by the VA Caregiver Program. Teaching them that there's more to them as a caregiver than just-- that they don't have to be listed on a piece of paper that says that they are the caregiver. Self-care is a really big one. A lot of people don't know how to do self-care for themselves, and they don't know how to manage their time to be able to do self-care. I mean, it can be as simple as just going out for a walk or something relaxing and they don't really realize that that is considered self-care or how to figure that into their schedule. And I definitely do think that educating them on programs and retreats that are geared towards brain injury families are real important because for one, there's not a whole lot of them. And two, those kind of things are totally different. A totally different atmosphere than just regular retreats and get-togethers with the veterans. They're all equally important but it's just a whole different dynamic when you're dealing with brain injuries.

Welch: It's interesting that you say there's actually not many because, at least according to the Rand study that estimated there was something like 5.2 million military caregivers and then of that number, 30% of those folks were dealing with the results of a sustained traumatic brain injury. So that's up near 1.6 million folks who, among other things, obviously, are dealing with the symptoms and sequelae of traumatic brain injury. So that tells us that, with the numbers that we've had listening to the podcast-- which it's about somewhere between 700 an episode and 150 an episode-- that there's a lot of people we aren't reaching. So what are the recommendations that you would have, and I'll start with you Emily. What are the recommendations that you would have to let more caregivers know about this podcast and so we could help them out and get them more information?

Mather: Well, I think that one of our greatest assets is social media. To be able to promote these programs. They make fliers images that you can share. I think that those are probably our best line of defense to be able to bring more people to the table. There's a lot of organizations-- I have a page on Facebook. I don't always keep up with it real well because I being a caregiver I'm pretty busy myself. But, it's called Celebrating Heroes. And, it's the information and referral site to be able to share with the military community. So, it's not just for military families, or veterans, or spouses. It's for anybody. Anybody that wants to gather that information, because you never

know if they have a friend a family member that is in that situation that is not connected to anyone or anything. And, maybe they're the only one that's providing them with information that could help them get resources.

Welch: And, Melissa, how about you. Do you have any recommendations about how we could let more people know about this podcast?

Meadows: I actually agree wholeheartedly with Emily regarding the social media. Social media is pervasive. I mean, it's-- Even my grandmother was on Facebook and she was 80 some odd years old before she passed away. I mean, I think social media is really the key to getting the information out. But, we still, we can't overlook the old-school ways of a simple ad in the paper, or putting a flyer in somewhere, or hanging it up in TBI clinics. Things like that, because often times I don't catch things on Facebook myself. I just heard about your page. I'm going to be looking it up after this. But, when I'm at a VA clinic, I'll see flyers, and I'm like, oh, that caught my attention. Hmm. And, I'll snap a picture of it or I'll take it off. And then, I share it on my Facebook page and on the caregiver pages that I'm involved in. So, social media, it's a little of old-school, and then it's just word of mouth. We've gotta take care of each other. So, like Emily said, a lot of times people they don't necessarily identify themselves as caregivers. But, they also don't necessarily catch the ads. So, we have to educate everybody as much as we can. People who are watching out for their friends, their neighbors, their cousins, their aunts, or uncles, whatever. It's word of mouth, social media, and old-school. I think it's a combination of all of them. But, getting that information out there is just so key. And, I'll share the heck out of anything, anything that's good for our service members and their caregivers obviously, so.

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Livingston: One thing Emily and Melissa made clear in their discussion was that many people still aren't sure how to listen to podcasts. If you're a listener to this podcast, and a member of a caregiver social media or support group, we'd really appreciate it if you could ask your fellow group members if they've heard about the TBI family. And, if they know how to listen and subscribe to podcasts. If you haven't subscribed yourself, please do. You can review the podcast on your podcast app which also helps others find the show. Or, you can send us an email at info@dvbic.org. That's I-N-F-O@D-V-B-I-C.org. As always, you can also send us questions about the podcast or about dvbic products or programs.

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TBI Family is produced and edited by Terry Welch and hosted by me, Dr. Scott Livingston. It is a product of the Defense and Veterans Brain Injury Center, commanded by acting director Kathy Helmick. And, the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, commanded by acting director Dr. Richard Stolts. Thanks this week to the Hunter Holmes McGuire Veterans Medical Center in Richmond. Melissa Meadows and Emily Mather. As always, thank you for listening.

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