Announcer: Welcome to the VA HSR&D investigator insights podcast series. In this episode, QUERI dissemination coordinator Diane Hanks speaks with Lisa McAndrew, research scientist and acting director of research and fellowship at the VA New Jersey Healthcare Systems War Related Illness and Injury Study Center. They’re discussing her work on Gulf War illness.

Diane Hanks: … what is Gulf War illness because for a long time that wasn’t defined. Has it been defined?

Lisa McAndrew: That’s a great question and I think there isn’t a universally agreed upon definition. The National Academy of Medicine has recommended two case definitions which essentially both of them say that veterans have chronic fatigue, chronic pain with other symptoms in other systems, so GI symptoms, neurocognitive symptoms. They don’t have to have all of them, but usually three out of six domains is the general idea. I usually explain that it’s like chronic fatigue syndrome or fibromyalgia.

Diane Hanks: Is there a checklist in order to help with a diagnosis?

Lisa McAndrew: We don’t have a checklist like that and that’s because we don’t have a very clear answer on

Diane Hanks: Cause and effect?

Lisa McAndrew: Yes. I think there’s growing agreement that it’s related to deployment, there were exposures, but exactly how those are related and lead to Gulf War illness is not known.

Diane Hanks: Is it easier now or is it still difficult for veterans to get that kind of diagnosis?

Lisa McAndrew: It’s definitely difficult for them to get that diagnosis. For one, it’s not an ICD10 code. It’s not something that providers could just click the box and say yes. Most providers we talked to say I wasn’t trained about this. Like nobody talked about Gulf War illness. So we just did a chart review of 200 veterans who we think have Gulf War illness based on the case definition and we looked for any sign in their medical record if they have a diagnosis. We looked for chronic fatigue syndrome or fibromyalgia or anything that suggested that the provider was picking up on it. 30% of Operation Desert Storm, Desert Shield we think have Gulf War illness. Out of those we are finding only 35% have it in their medical record.

The Gulf War is still continuing and so while Gulf War illness was the signature condition after Operation Desert Storm, Desert Shield, we have done some work to find that it’s highly prevalent for OEF, OIF, OND veterans. We don’t know is that the same thing, what’s going on.

Diane Hanks: Or is it different?

Lisa McAndrew: Is it different? We don’t typically call it Gulf War illness after Operation Desert Storm, Desert Shield. We refer to it as like chronic multi-symptom illness.

Diane Hanks: Can you explain a little bit about satisfaction and adherence to problem solving treatment from Gulf War illness? And if you have any findings?

Lisa McAndrew: We just completed the second largest clinical trial for Gulf War veterans with Gulf War illness. We randomized 268 Gulf War veterans to either receive something called problem solving therapy, where we taught them skills to overcome brain fog or problem-solving impairment to improve their daily life. We compared it to a health education. Both were delivered remotely, an hour a week for 12 weeks. What we found was that over 90% were adherent to these treatments.

Diane Hanks: Oh wow.

Lisa McAndrew: To all 12 sessions. And over 90% were highly satisfied with it. We set out to develop a treatment that veterans wanted to receive and so we’re really excited that they wanted to receive these.

Diane Hanks: What is the median age of the veteran in that cohort?

Lisa McAndrew: 50.

Diane Hanks: Oh. The only reason I asked about age is I wondered if the age had something to do with adherence.

Lisa McAndrew: We did look at the adherence to other clinical trials for Gulf War illness and it’s a not a fair comparison because there’s different treatments, but we did find higher adherence than has been seen in other clinical trials including one we did.

Diane Hanks: Okay.

Lisa McAndrew: We do think

Diane Hanks: It had something to do with the treatment itself?

Lisa McAndrew: The treatment. Although I mean you mentioned age and that is a growing complexity in this population because they have other comorbid conditions that are popping up.

Diane Hanks: Right and everything is getting more complicated.

Lisa McAndrew: Everything is getting more complicated.

Diane Hanks: Can you tell us about the veteran engagement and telehealth treatment study and how it was working with the veterans and what the telehealth treatment was? In particular was it phone, was it video?

Lisa McAndrew: Sure. I just told you about the clinical trial that we completed. What we proposed afterwards is to do … we know it’s not enough to develop efficacious treatments. We have to figure out how can we deliver them in the healthcare system. The next study that we will be doing will be answering that question. Should these treatments that we just developed and veterans liked be delivered out of primary care or specialty care?

Diane Hanks: What was it like working with veterans as contributors to the study design and development?

Lisa McAndrew: We got to talk with veterans, sat in front of an audience about that study and asked them are we getting it right, what are we getting wrong, how can we engage you?

Diane Hanks: And did they feel good about being part of the process and being able to contribute and

Lisa McAndrew: I hope so. I certainly appreciated hearing their voice. I know the whole team did. I think it was nice that we got to do it in front of an audience so everyone could learn because they’re the real experts. They’re living with it.

Diane Hanks: Is there anything else that you would like to talk about?

Lisa McAndrew: Yeah, so I think we are increasingly looking at how should providers talk about this with Gulf War veterans. We didn’t talk about the fact that the impact Gulf War illness is made more complex because they often receive inadequate healthcare so they’re highly dissatisfied. They don’t get evidence-based treatments. How do we fix that?

Diane Hanks: How long did it take before the VA would treat or recognize Gulf War illness after those veterans returned home?

Lisa McAndrew: It’s been a process. I think everyone is trying their best. I think we didn’t have a name for it. We didn’t have an understanding. So most veterans I talked to tell me that they’ve been told they’re malingering, or they have a mental health condition. Mental health conditions are highly comorbid. It’s not only

Diane Hanks: That’s not the definition of this illness.

Lisa McAndrew: Right, of this illness.

Diane Hanks: So then they probably feel stigmatized.

Lisa McAndrew: Yes. I think you're right. I think there’s a lot of distrust of medical providers in general, VA medical providers. In a lot of ways it makes me even more proud that we got the adherence and satisfaction we did because you’re right, it’s something we need to build in time into everything we do with population who’s been marginalized for so long to be build that trust back.

Diane Hanks: Do you know if they were seeking care outside of VA?

Lisa McAndrew: That’s a great question. I don't think anyone has looked at that. We certainly find a lot of the veterans we work with are seeking care in the VA, but also have had some outside the VA care.

Diane Hanks: And coordination of care, especially for this, I imagine is going to be tricky.

Lisa McAndrew: It’s tricky even if you’re just talking about in the VA.

Diane Hanks: Yeah.

Lisa McAndrew: And that’s what the veterans tell us, that I don’t know who’s in charge, no one’s in charge, I’m kind of getting shuffled from provider to provider. I think it’s with good intent. The provider sees somebody, they don’t know the answers, so they say well, you have GI problems, let’s go figure that out and

Diane Hanks: Maybe we need mental health pacts. Maybe we need a GWI pact that has a team of providers that are knowledgeable about that particular illness.

Lisa McAndrew: I agree and that’s exactly the study we’re doing. It’s a collaborative care working with the pacts.

Diane Hanks: Great.

Lisa McAndrew: The idea is in England actually they have specialists for chronic fatigue syndrome. If you ask primary care providers what’s the most complex condition you treat, they will tell you it’s these symptom-based conditions. I think it’s because when you think about cancer or heart failure, when they have a tricky case, they have a partner to work with. But in this, you don’t.

Diane Hanks: And that’s what you need.

Lisa McAndrew: We need that. That will be

Diane Hanks: That’ll be the future step?

Lisa McAndrew: Invite me back in four years and I’ll tell you. [laughs]

Diane Hanks: Okay. I don’t think we touched on operational partners. Do you have one?

Lisa McAndrew: We are at the War Related Illness and Injury Study Center, which is a congressionally mandated center that has an education, research and clinical mission. We’re kind of our own operational partner. Above is PDH which is office of post deployment health. This is the charge.

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