

Patient Centered Care for Chronic Multi-symptom Illness

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The views of the authors do not necessarily reflect the views of the federal government.

IK2 HX001369-01A1 (PI McAndrew)
Problem-Solving Therapy for Gulf War Illness

IO1 HX001678-01 (PI McAndrew, Co-PI Helmer)
WRIISC as a Model of Care for Chronic Multisymptom Illness

IO1 CX001053-03 (PI McAndrew)
Cognitive Rehabilitation for Gulf War Illness

Poll Question #1

- What is your primary role in VA?
 - Student, trainee, or fellow
 - Clinician
 - Researcher
 - Administrator, manager or policy-maker
 - Other

Poll Question #2

How much knowledge do you have about Chronic Multisymptom Illness (CMI)?

1. Expert
2. High knowledge
3. Some knowledge
4. Low knowledge
5. No knowledge

What is Chronic Multisymptom Illness (CMI)?

Experience of CMI is exacerbated by poor healthcare.

Patient-Centered Care of CMI

What is Chronic Multisymptom Illness (CMI)?

- CMI is a prevalent, disabling and poorly understood post-deployment health problem.
- Presumptive illness of ODS/S & OIF

Experience of CMI is exacerbated by poor healthcare.

- Veterans with CMI are unsatisfied with VA care.
- There is discordance between Veterans and providers goals, nature and cause of CMI.

Patient-Centered Care of CMI

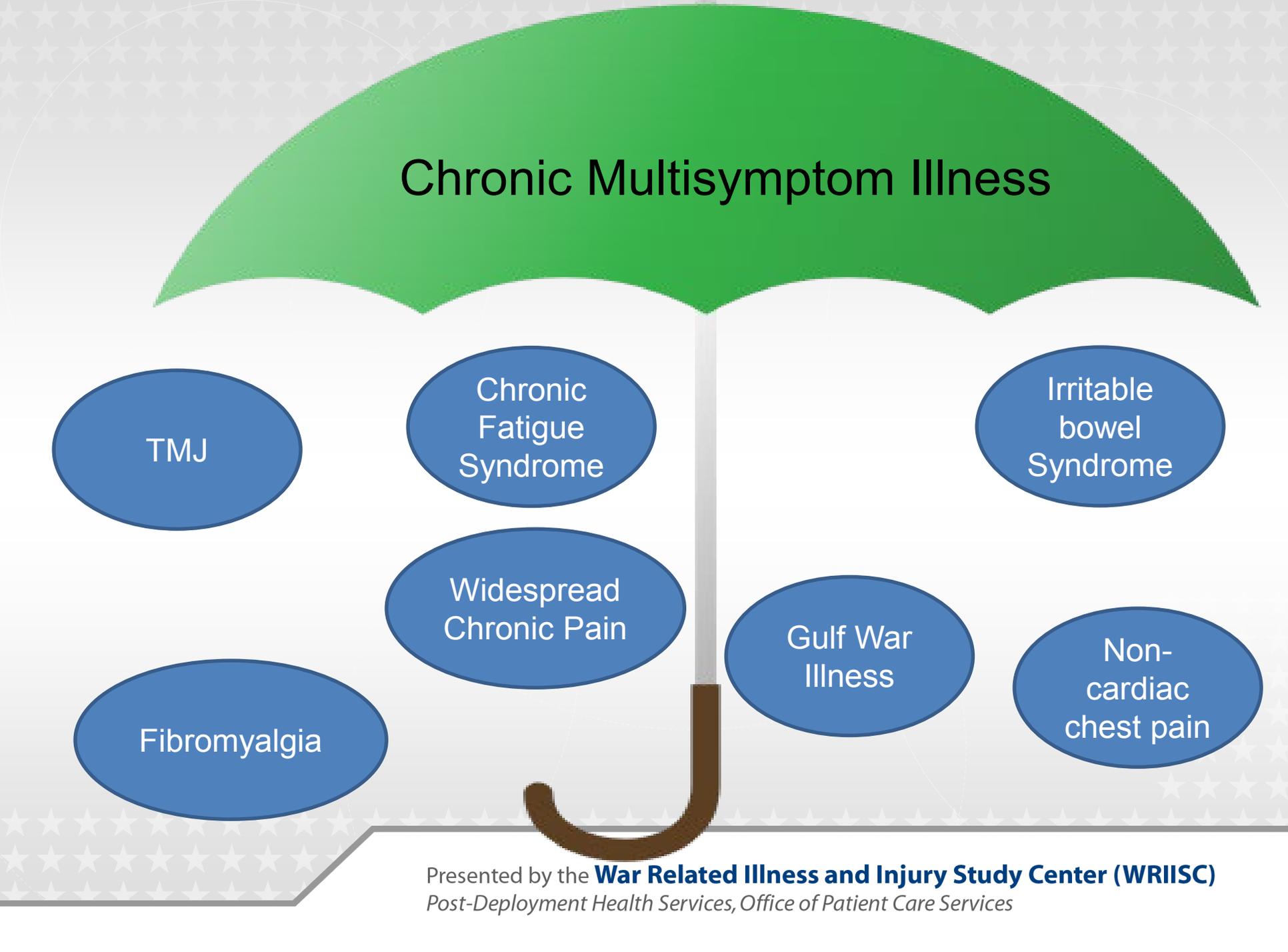
- Veterans want treatments that are consistent with their views of CMI and provide specific recommendations.
- Using this approach, we created a behavioral intervention for CMI that has high satisfaction and high adherence among Veterans with CMI.

What is Chronic Multisymptom Illness (CMI)?

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Patient-Centered Care for CMI

Chronic Multisymptom Illness



TMJ

Chronic
Fatigue
Syndrome

Irritable
bowel
Syndrome

Fibromyalgia

Widespread
Chronic Pain

Gulf War
Illness

Non-
cardiac
chest pain

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Combat and Physical Symptoms

There has been an increased reporting of physical symptoms after every war since the US Civil War (Hyams, 1996).

- Fatigue
- Shortness of Breath
- Headaches
- Sleep disturbances
- Forgetfulness

Operation Desert Shield/Operation Desert Storm



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Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF)

Study: Symptoms of 'chronic multisymptom illness' may be common in Iraq, Afghanistan... Page 1 of 4

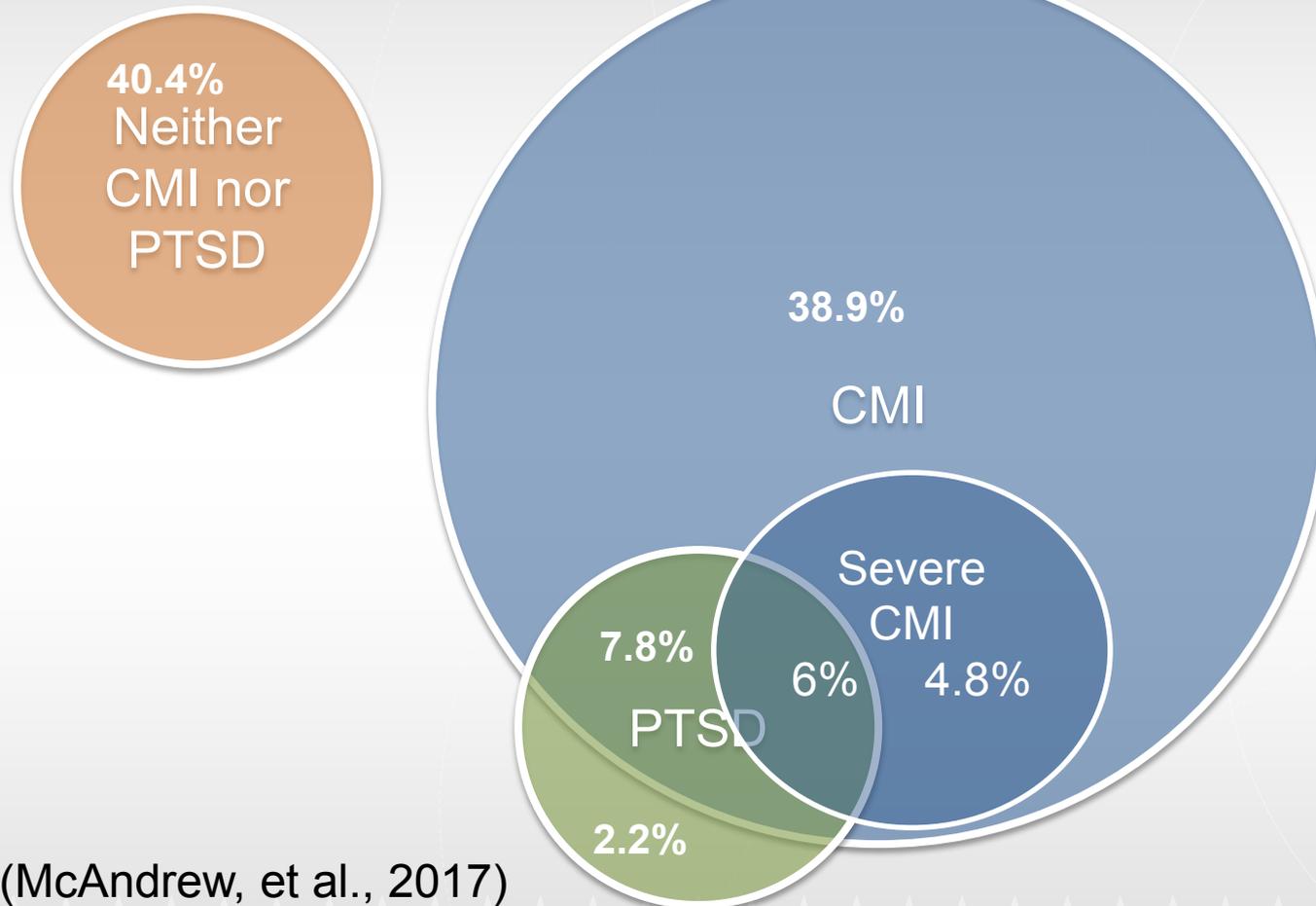
PUBLIC RELEASE: 13-MAY-2016

Study: Symptoms of 'chronic multisymptom illness' may be common in Iraq, Afghanistan vets

VETERANS AFFAIRS RESEARCH COMMUNICATIONS



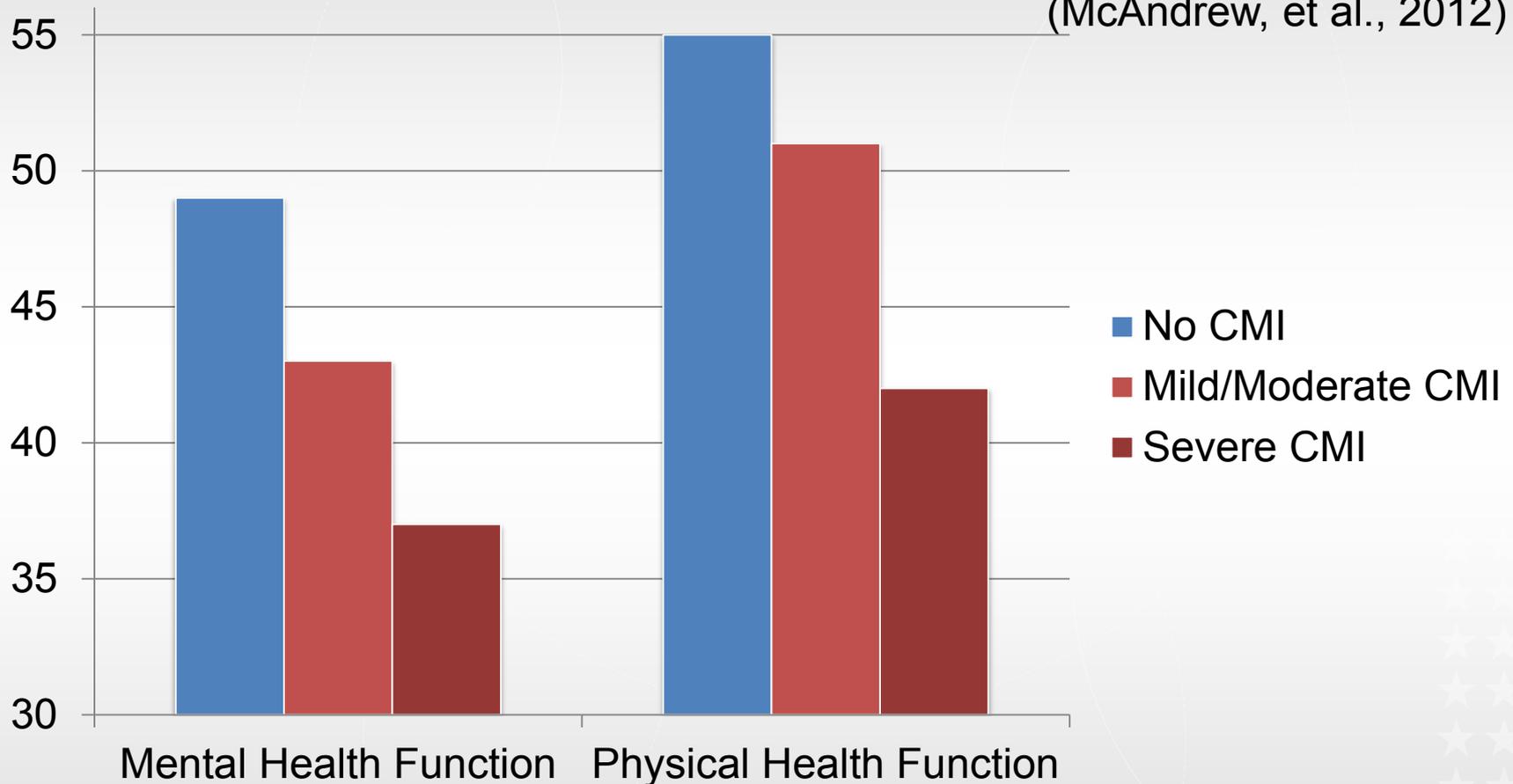
CMI and PTSD one year after OIF/OEF deployment



(McAndrew, et al., 2017)

CMI causes Disability

(McAndrew, et al., 2012)



* All differences between means are clinically and statistically significant

Operation Desert Shield/Storm & Iraqi Freedom

GULF WAR PRESUMPTIVE ILLNESSES



CHRONIC FATIGUE SYNDROME

A condition of long-term and severe fatigue that is not relieved by rest and is not directly caused by other conditions.



FIBROMYALGIA

A condition characterized by widespread muscle pain. Other symptoms may include insomnia, morning stiffness, headache, and memory problems.



FUNCTIONAL GASTROINTESTINAL DISORDERS

A group of conditions marked by chronic or recurrent symptoms related to any part of the gastrointestinal tract. Functional condition refers to an abnormal function of an organ, without a structural alteration in the tissues. Examples include irritable bowel syndrome, functional dyspepsia, and functional abdominal pain syndrome.



UNDIAGNOSED ILLNESSES

With symptoms that may include but are not limited to: abnormal weight loss, fatigue, cardiovascular disease, muscle and joint pain, headache, menstrual disorders, neurological and psychological problems, skin conditions, respiratory disorders, and sleep disturbances.

Conclusions

- CMI is a prevalent, disabling and poorly understood post-deployment health problem.
- CMI is a presumptive illness of ODS/S & OIF.

What is Chronic Multisymptom Illness (CMI)?

Experience of CMI is exacerbated by poor healthcare.

Patient-Centered Care for CMI

CMI and increased healthcare utilization

- Veterans with CMI seeking care in the VA have twice the healthcare utilization as Veterans without CMI seeking care in the VA (Mohanty, et al., 2018).
- Veterans with CMI have healthcare utilization increases within one year of returning from deployment (McAndrew et al., 2017).
- VA Medical Records show that ~30% of Veterans with CMI are on long-term opioids (Mohanty, et al., 2017).

Patients and Providers feel CMI is extremely difficult condition to treat

“Difficult”

“Poor Coordination of care”

“Heartsink”

“I’m unsatisfied with my care. My doctor doesn’t believe me”

Are Veterans with CMI satisfied?

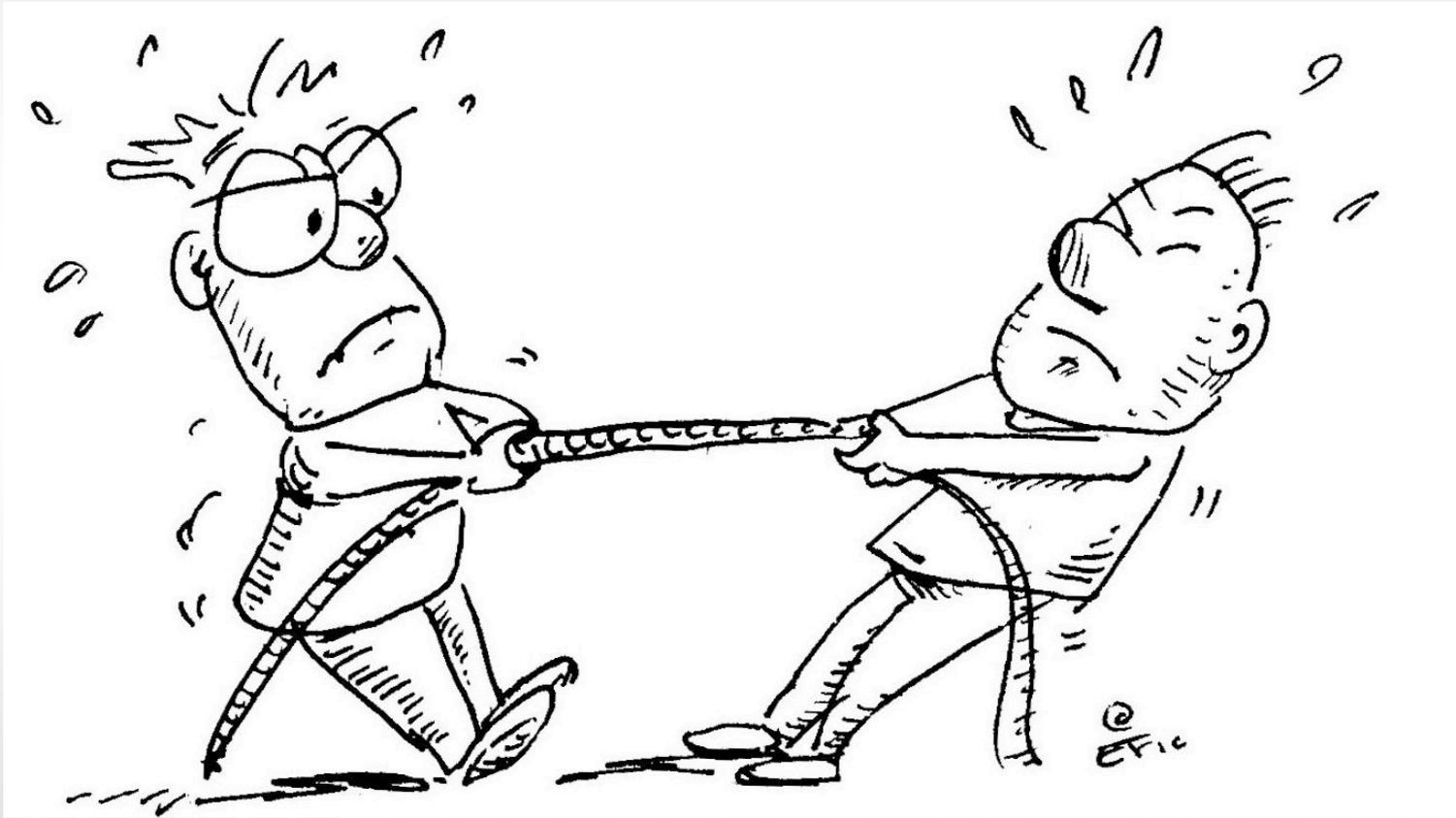
| Variable | Mean (SD) | Possible Range |
|---|-------------|----------------|
| CMI Treatment Adherence, Past 6 Months | 3.31 (1.41) | 1-5 |
| CMI Treatment Intentions, Next 6 Months | 3.77 (1.25) | 1-5 |
| Satisfaction with the Primary Care Provider | 3.39 (1.27) | 1-5 |
| Expectations for CMI Improvement | 2.38 (0.97) | 1-5 |

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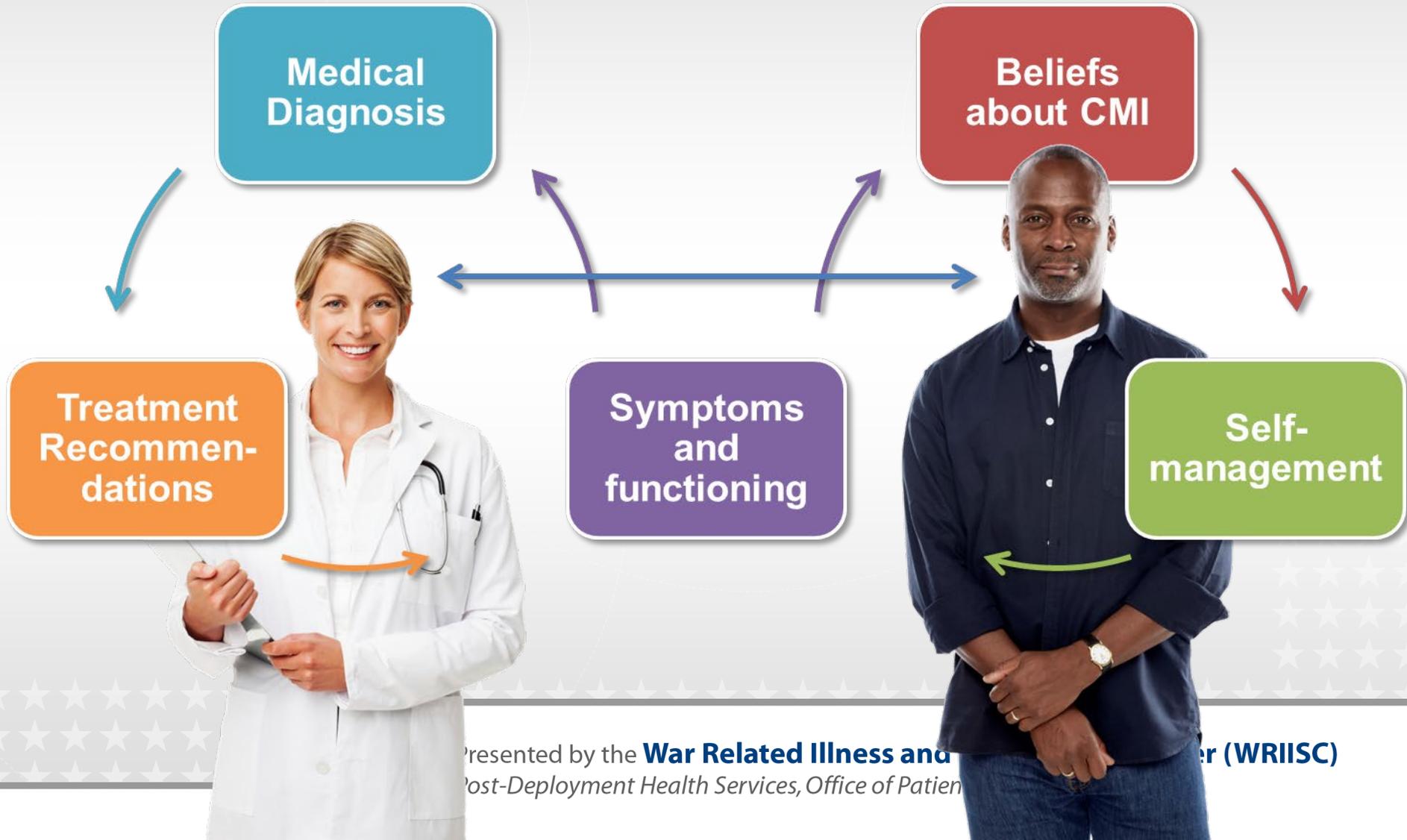
(Phillips, et al., In press)

**“When I use the term Gulf War
Illness with providers I get a
blank stare – so I don’t use it”**



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CMI Management



It's not all in my head

“I started getting these headaches and tender rashes on my legs like, I didn't think anything of it, I worked at a gym...

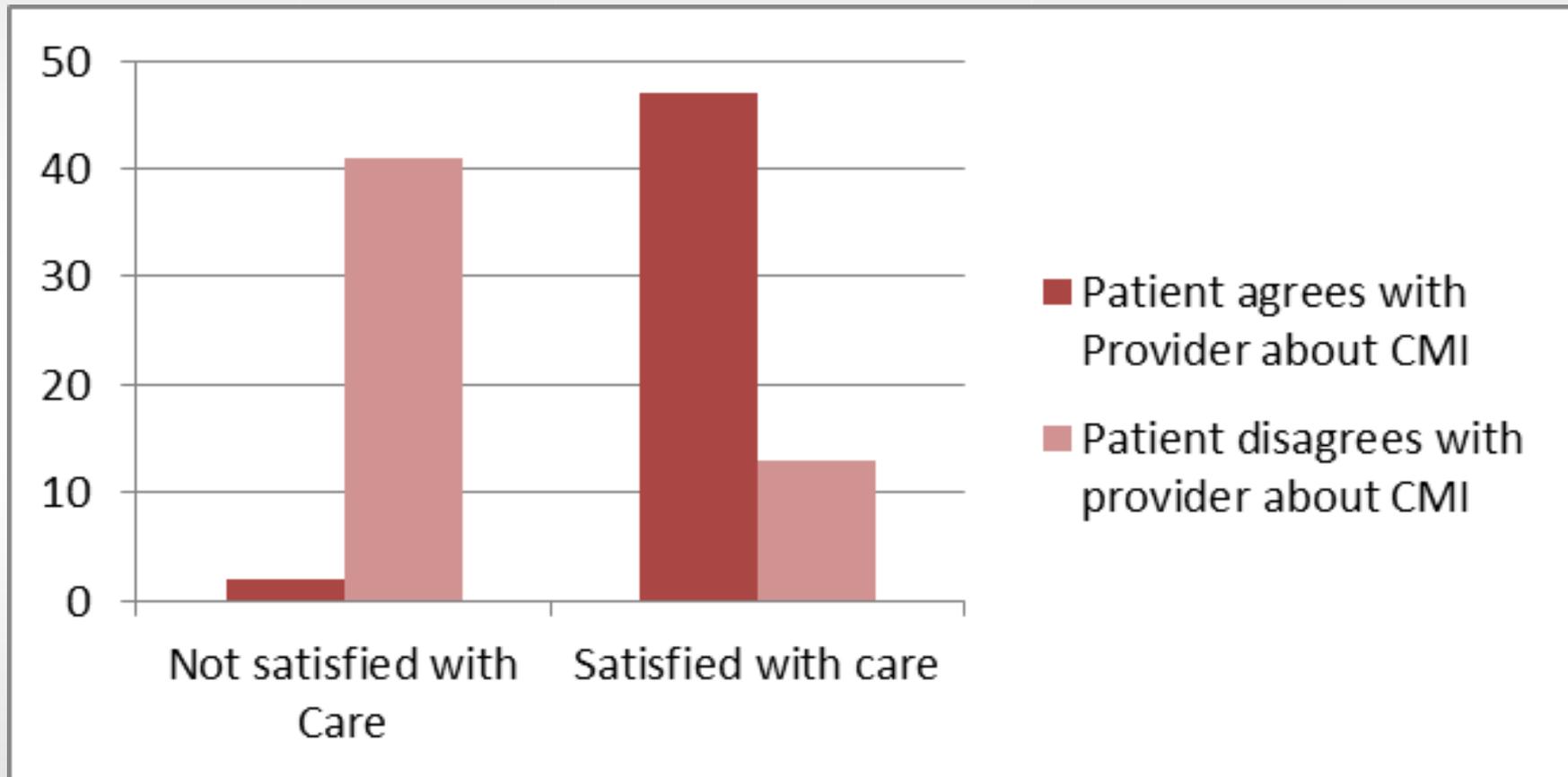
I had the headaches when I was over in Iraq but they got worse... when I got out I went to the VA in [city] and had a bad experience with a nurse. She told me everything was in my head so I never went back.”

(Hyde, et al., 2018)

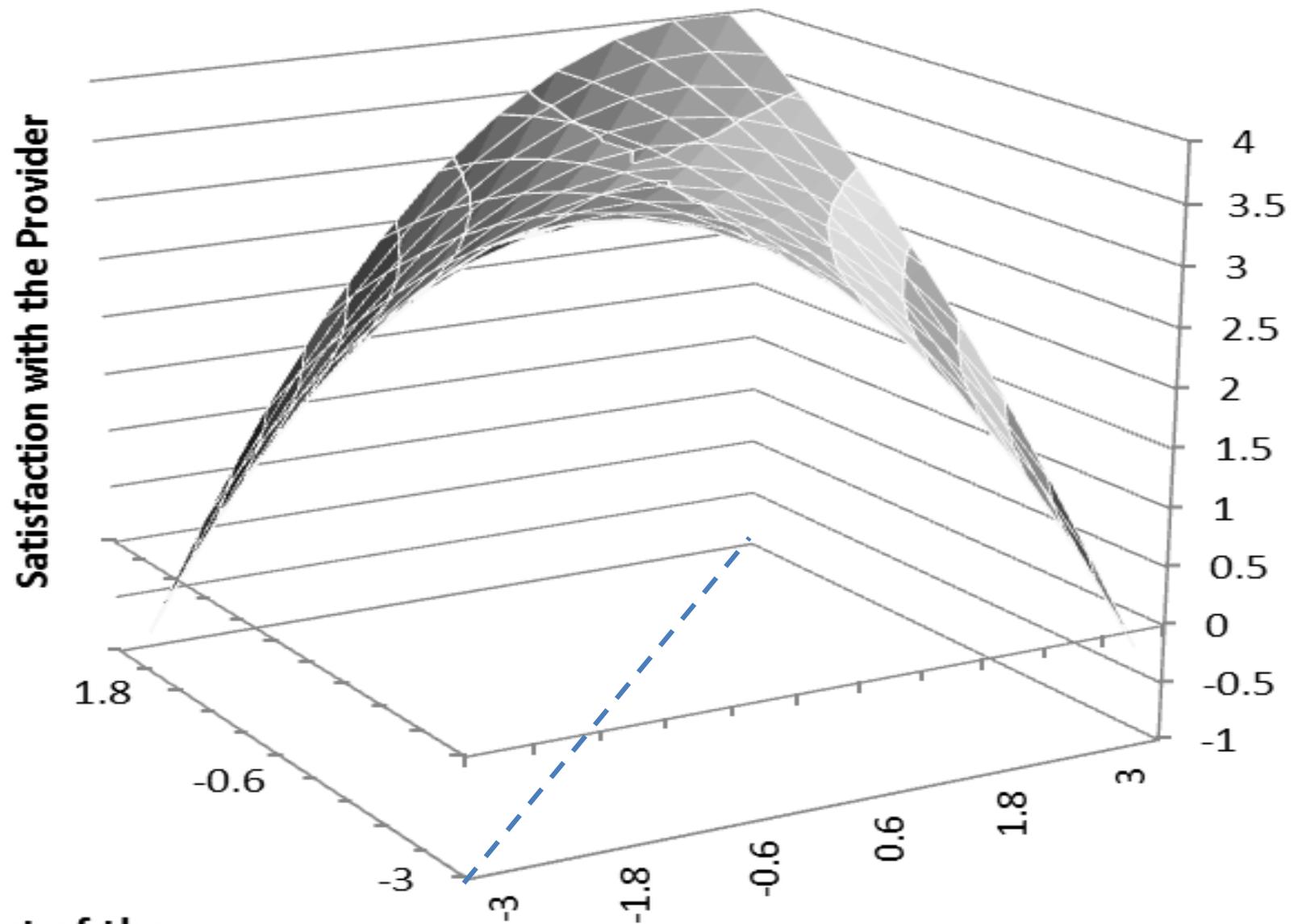
Where are the Experts?

[W]hen we first created military hospitals in this country ...they were staffed with the very best doctors ... The first question that they would ask ... is where in the world have you been? ... Someone should be asking me questions. – were you in Desert Storm? Nobody asks us or cares about specific health issues that we have per era as a Veteran... the people that I see at the VA should be experts at this.

Shared Illness Beliefs

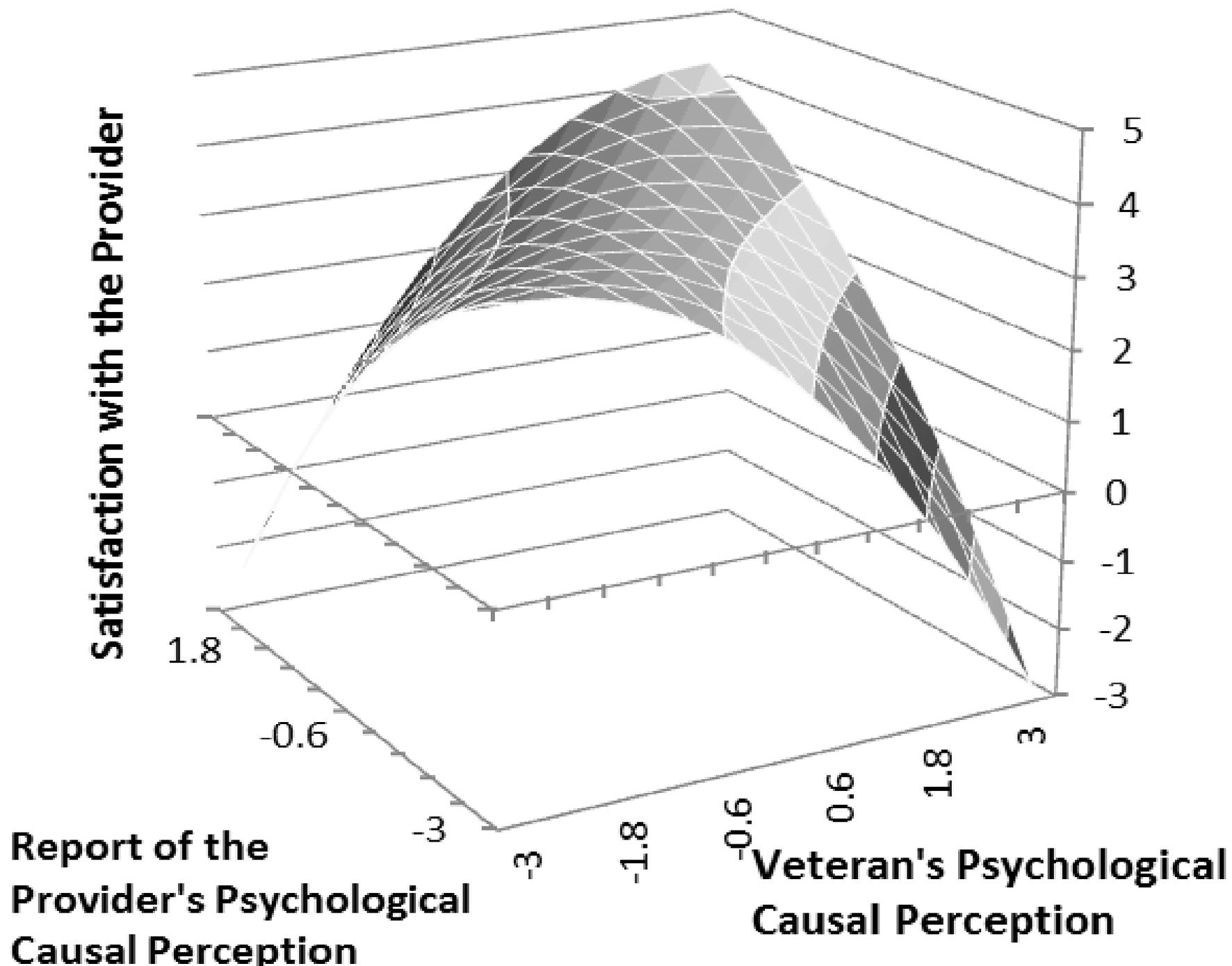


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**Report of the
Provider's Internal/Biological
Causal Perception**

**Veteran's Internal/Biological
Causal Perception**



Chronic Multisymptom Illness Management

Beliefs about
CMI



Conclusions

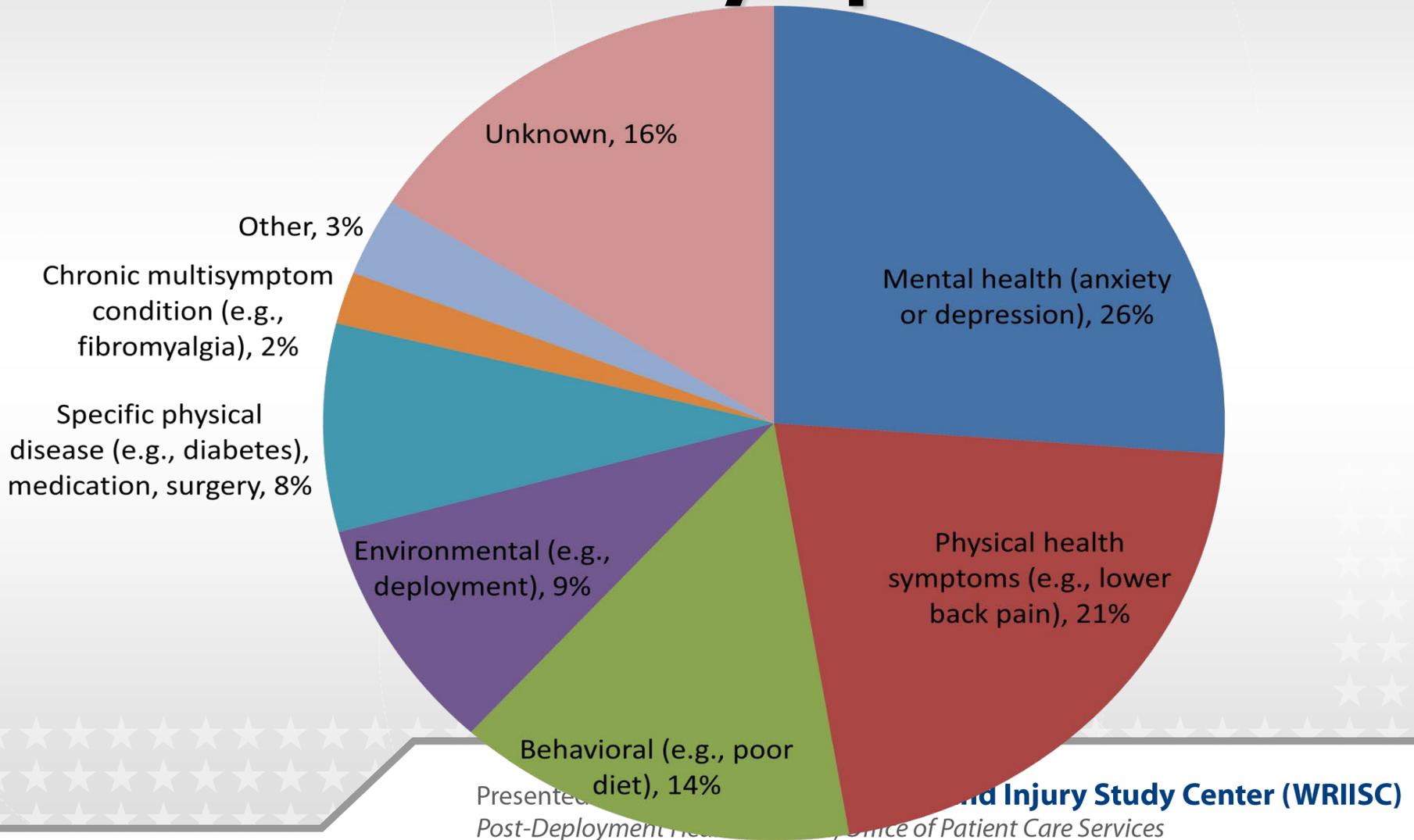
- Veterans with CMI are unsatisfied with VA care.
- There is discordance between Veterans and providers goals, nature and cause of CMI.

What are Chronic Multisymptom Illness

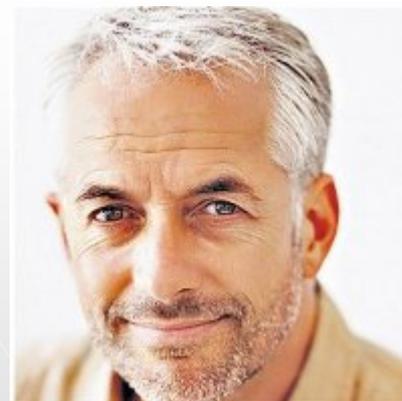
Veterans experience of CMI is exacerbated by poor healthcare.

Patient-centered care of CMI

Veterans Beliefs about the Cause of CMI Symptoms



Veterans with Chronic Multisymptom Illness want to Improve their Quality of Life



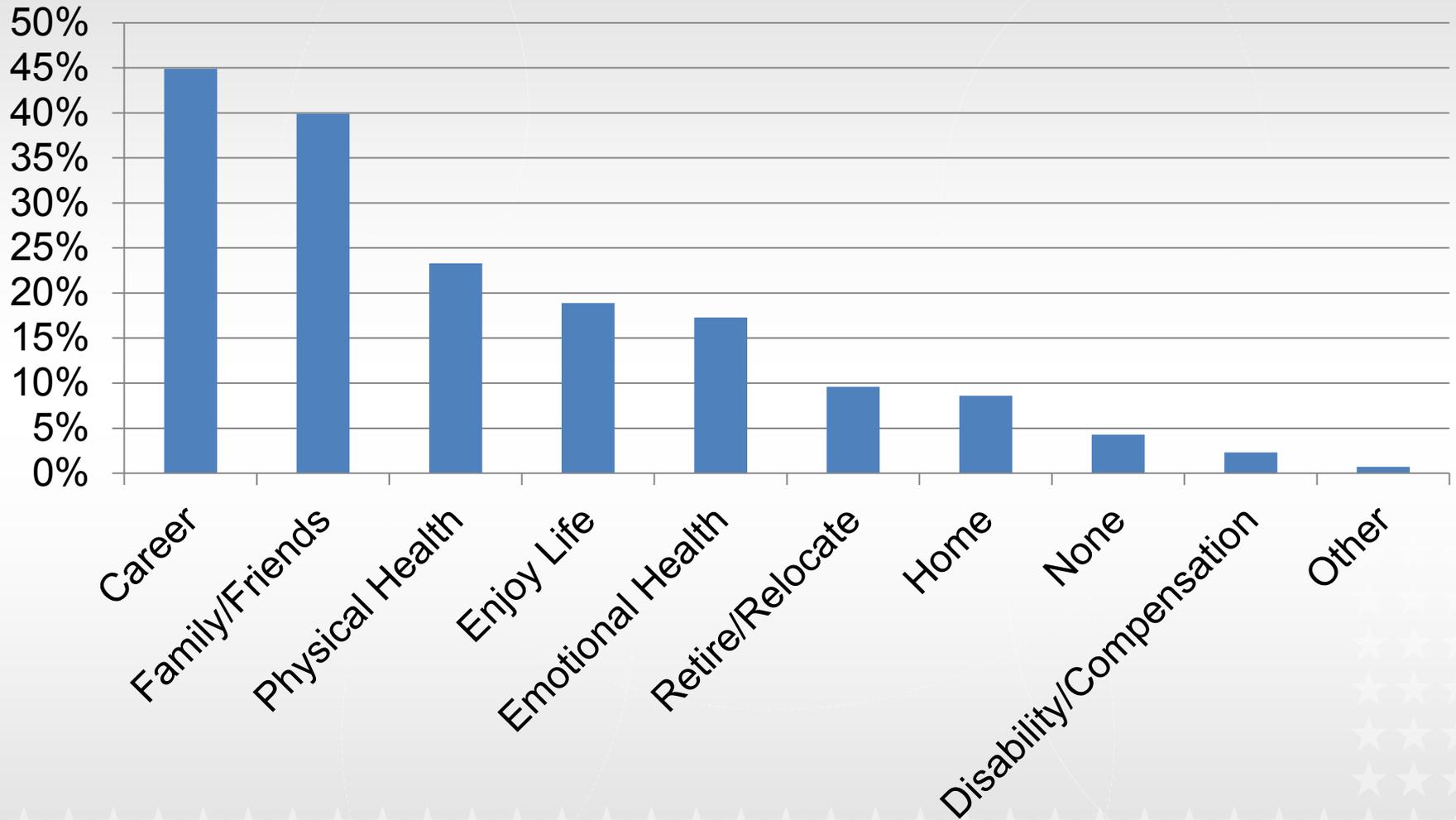
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81% of Veterans with CMI feel that it has Major Consequences on their Life

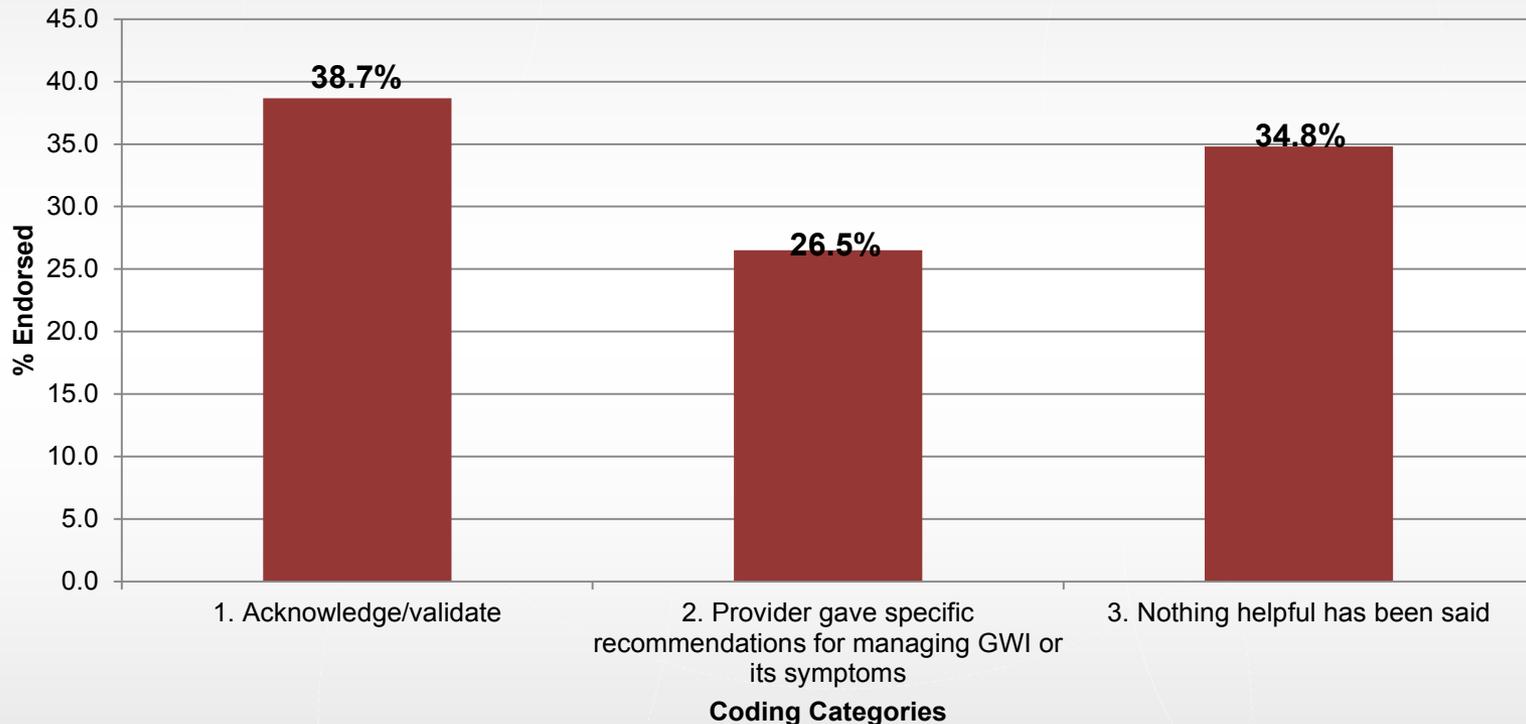


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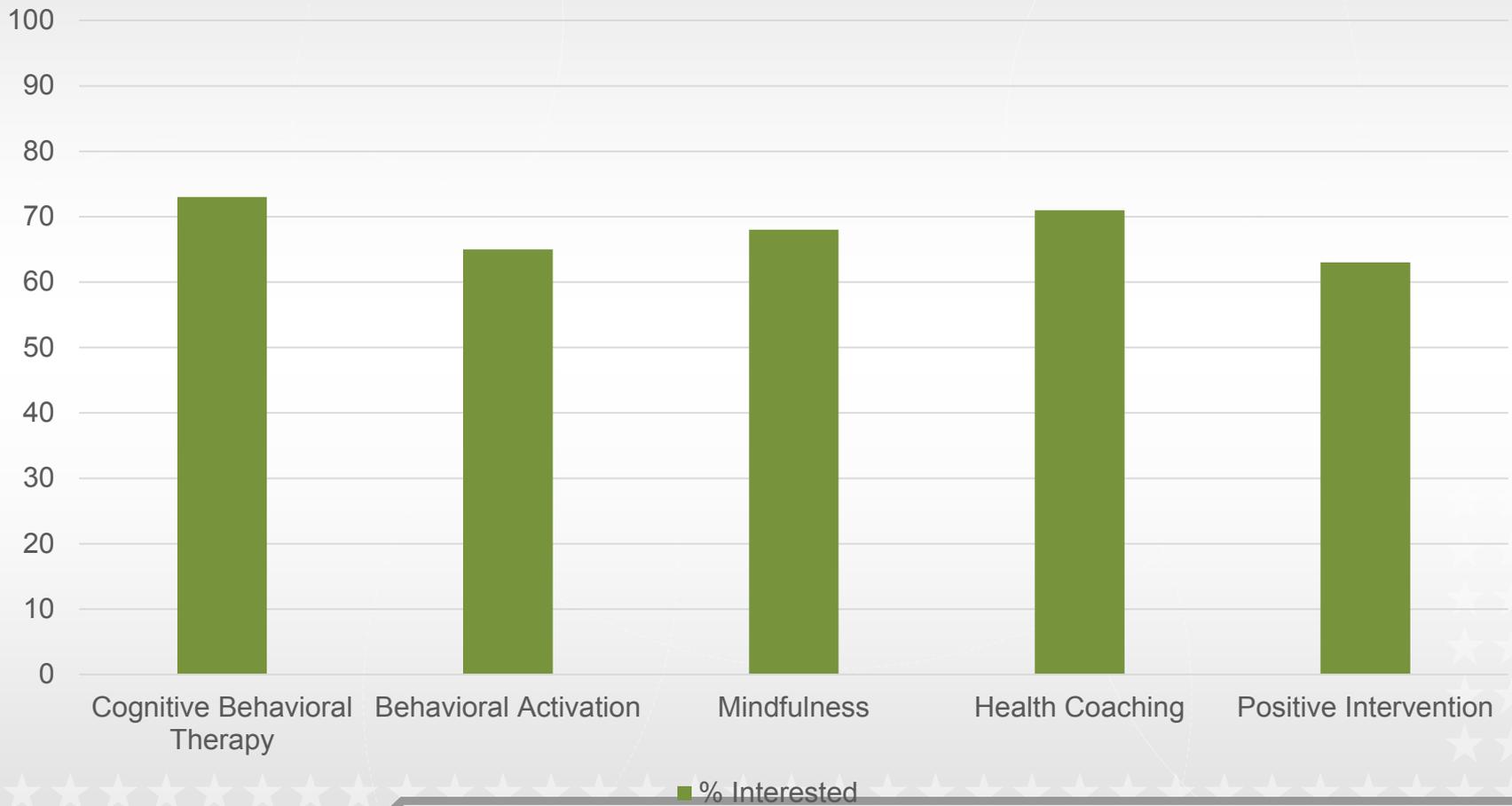
Goals



What is the most helpful thing a healthcare provider has said regarding your CMI?

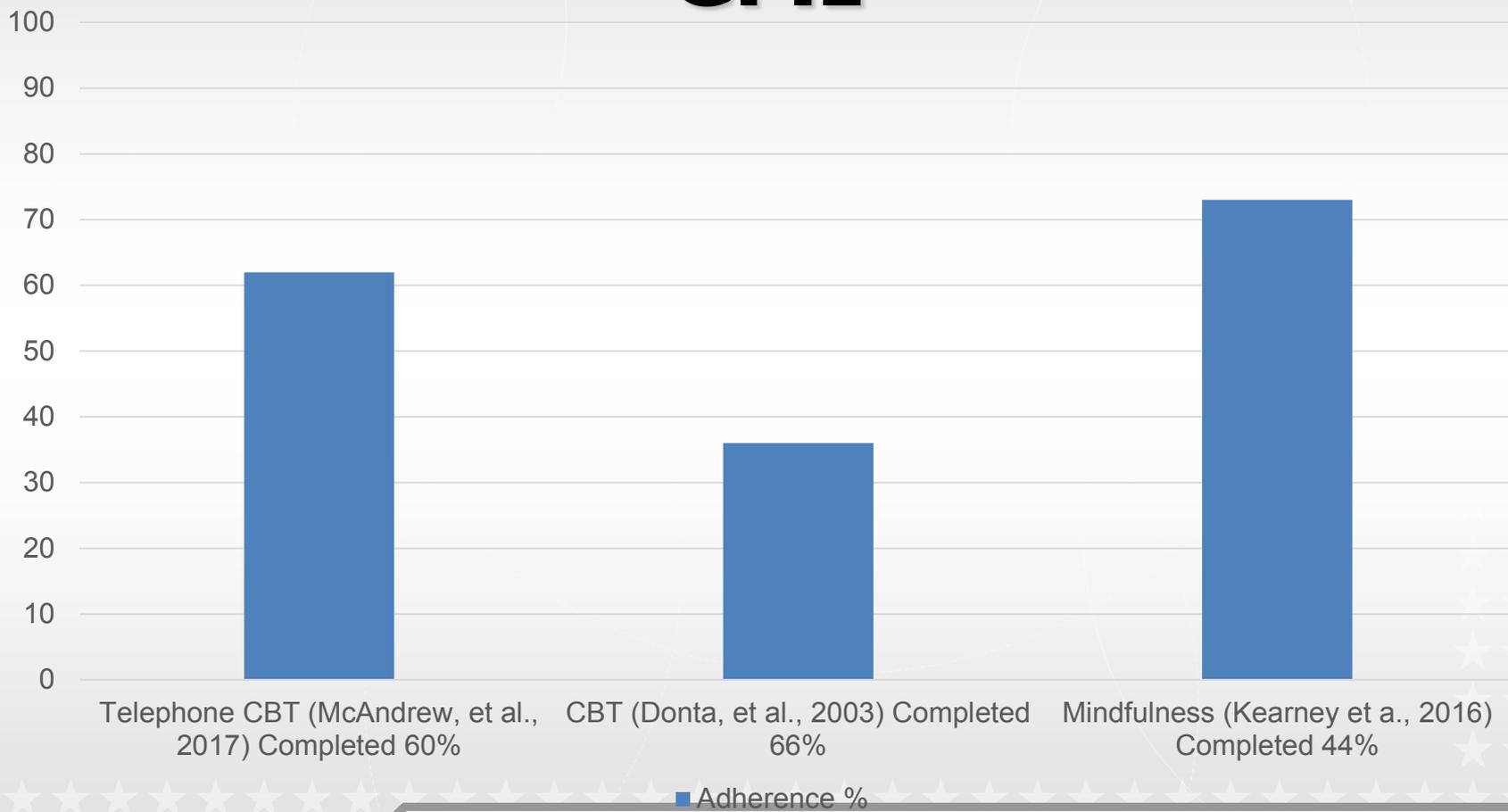


Veterans are interested in non-pharmaceutical treatments



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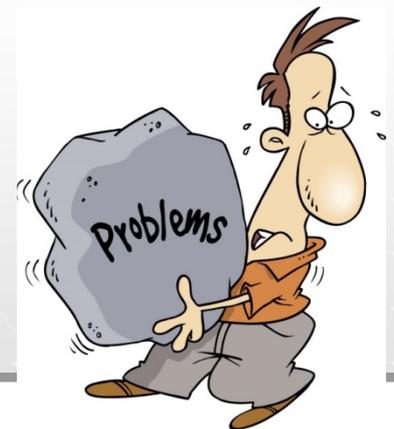
Relatively Low Adherence to Psychological Treatments for CMI



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Problem-Solving Therapy

- 12 sessions
- Listen to the Veteran GWI
- Understand their experience
- Teach them skills to improve quality of life

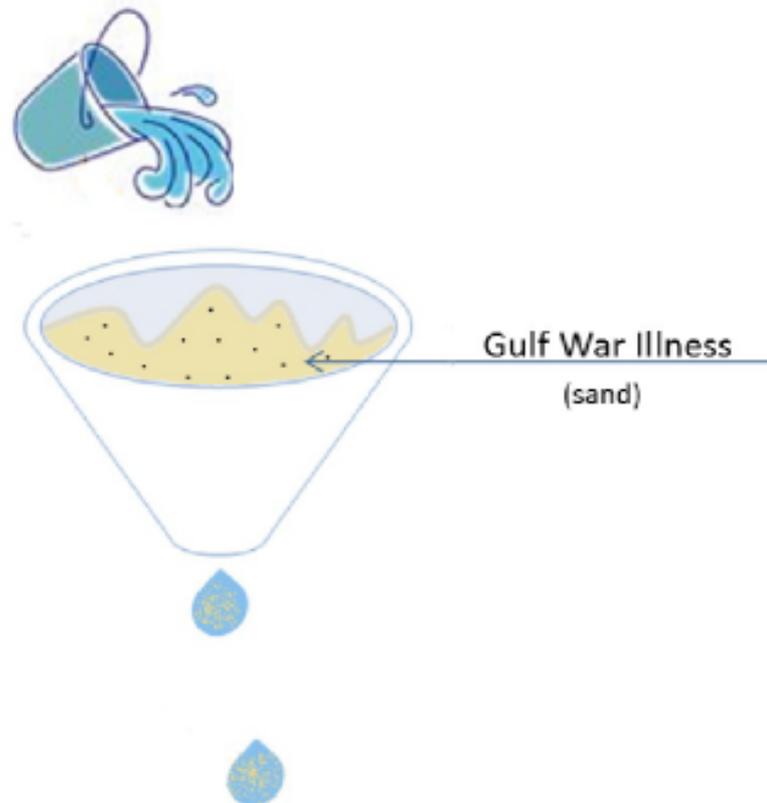


Why Problem-Solving Treatment (PST) for GWI?

GWI can cause slowed thinking and something called *brain fog*. Brain fog makes taking in, organizing, and acting on information more difficult. This can slow down everything from making little decisions to performing activities of daily living. Our attention, concentration and memory can all be affected. This can make it hard to make decisions. Brain fog impacts everything! Often people do not understand why it takes people with brain fog longer to accomplish tasks or why sometimes they may give up. This can lead to frustration and disappointment.

GWI doesn't impact your intelligence or how smart you are!

However, if you fill the funnel with sand, the water will slowly filter into the cup. With enough sand, the water may become clogged and any water filtered through will not be as clear.



Meeting 1: Getting to Know You

Double Whammy

Veterans with GWI might not only experience brain fog, but also often have chronic pain, fatigue and other physical symptoms. Chronic physical symptoms can create problems that make it very hard to do the things you want or need to do. Brain fog makes it hard to tackle the problems that prevent you from doing what you want and need to do.

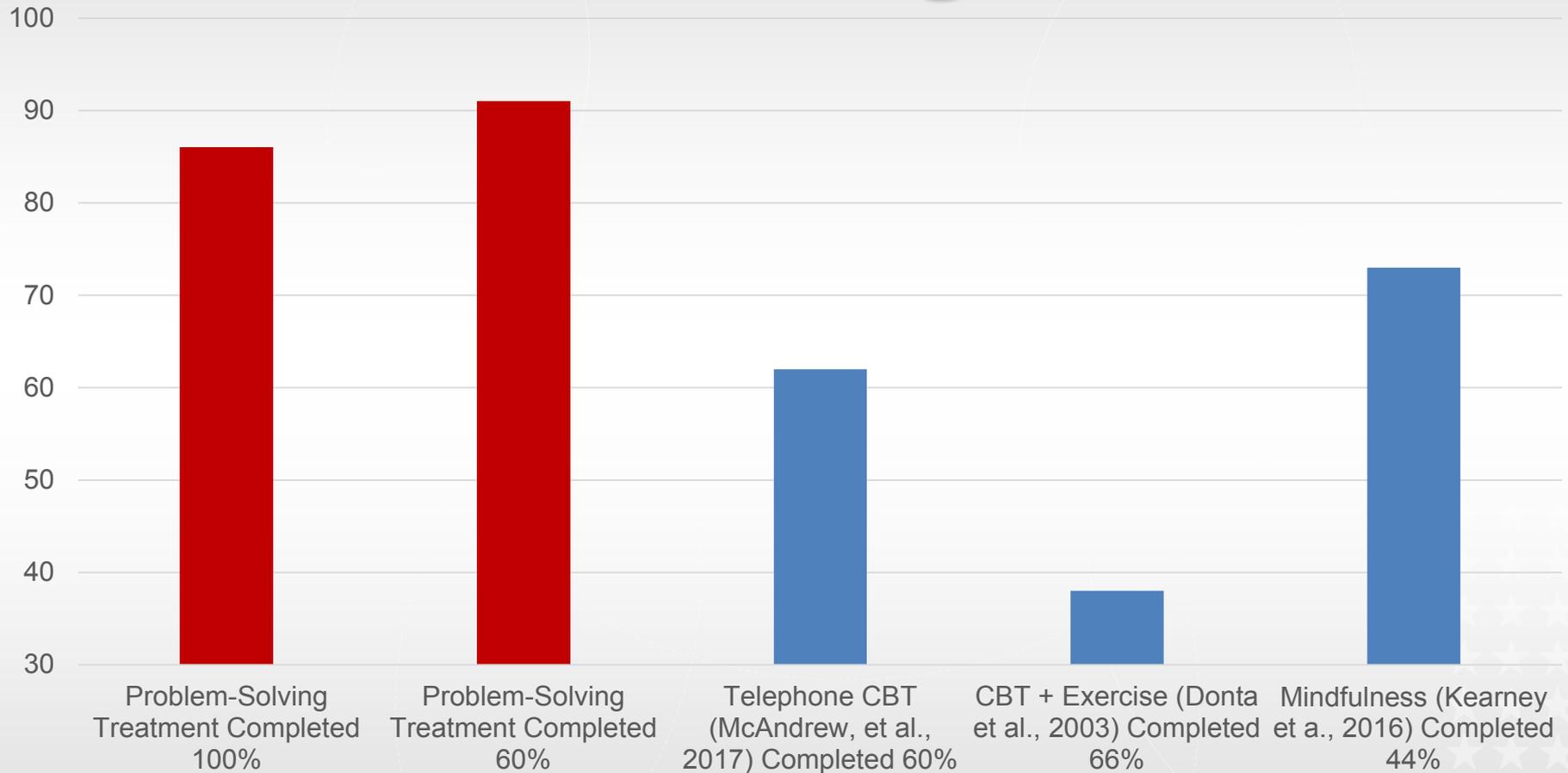
Here is an example from a Gulf War Veteran: “I attended a meeting on GWI in Washington, DC. I had to rest for two days before the meeting. I also had to make sure my hotel room was in the same building as the meeting so I could quickly go back to rest and use the bathroom. I called the hotel kitchen before I left to make sure that there were food options that wouldn’t make me sick. When I came home I was wiped out for a week. But I am glad I was able to go.”

In this example, the Veteran had to do a lot of planning to attend the conference. Extra planning is necessary with chronic physical symptoms, but brain fog can make it difficult to do this extra planning.

Problem-Solving Treatment (PST)

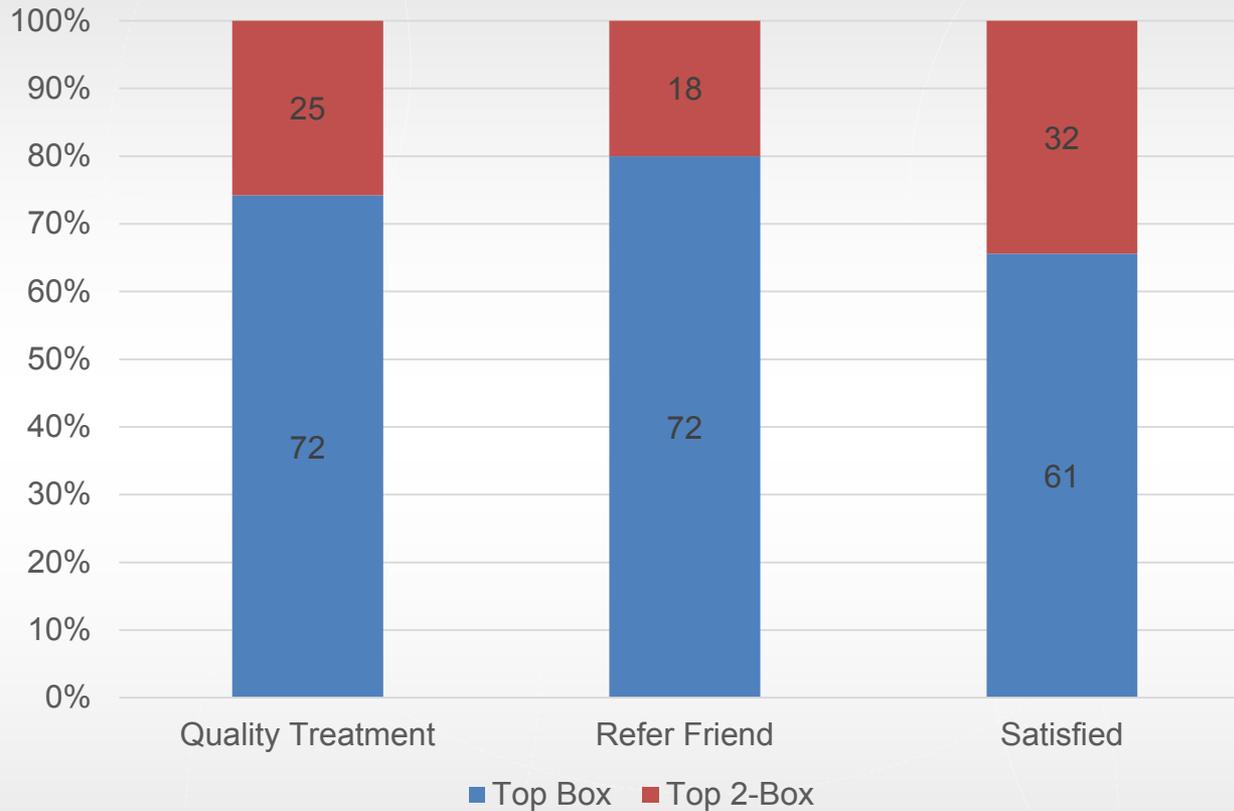
Fortunately, there is a treatment that can help and it is called “Cognitive Rehabilitation.” Problem-Solving Treatment is one type of cognitive rehabilitation. In this study you will work with a cognitive rehabilitation expert (study provider)

GWVs with GWI are Adherent to Problem-Solving Treatment



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Satisfaction



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Veteran's experience of Problem-Solving Therapy

“The most nagging situation in my life is I can't accomplish things and that is where [the problem-solving therapy] has helped...That makes me feel better. That is who I was and what I was before the Gulf. I was a problem-solver. This program gives me hope.”

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Thank you

Questions?

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