Chronic Pain after TBI

Jeanne M. Hoffman, PhD

Professor, Department of Rehabilitation Medicine, University of Washington School of Medicine USA

Risa Nakase-Richardson, PhD

Associate Chief of Staff for Research, James A. Haley VA,

Professor, Department of Internal Medicine, University of South Florida USA

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. List the most frequent types of pain and role of comorbidities in individuals with TBI and chronic pain.
2. Describe how pain and treatment can differ based on examination of extreme phenotypes.
3. Discuss possible barriers and facilitators for engagement in pain treatment for individuals with TBI.

The Experience of Pain after TBI

What was known about chronic pain after TBI

Research from our group has shown:

- High rates of headache (1/3) up to 5 years post injury. Up to 71% of TBIMS participants reporting pain at 1 year post injury.
- Up to 81% of VA PRC TBIMS participants reporting pain.

Despite high rates of pain after TBI, many people are not receiving treatment.

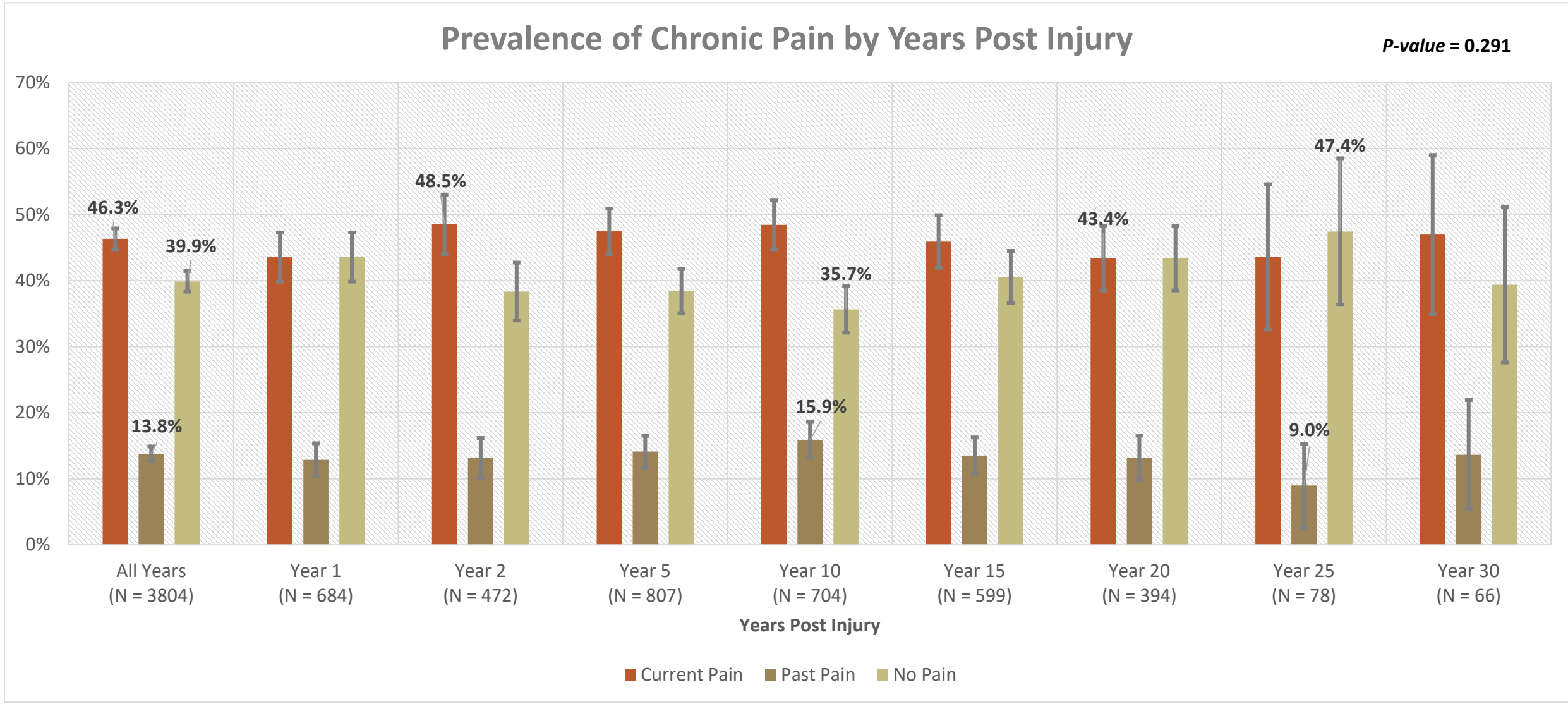
Brief overview of the Study

Persons with moderate to severe TBI who are already enrolled in the TBIMS National Database from 18 centers.

Enrolled 3,804 participants across all follow-up time points.

Participants were recruited when they were contacted for one of their routine TBIMS follow-up interviews at 1, 2, 5, and every 5 years post-injury thereafter for Aims 1 and 2.

Providers were recruited through email/listserv introduction of the study to learn about barriers to pain treatment.



60.1% Current or Past Pain (All Years; Range 52.6% to 64.3%)

The experience of chronic pain:

- Pain Intensity (0=No Pain to 10=Worse Pain): Average of 4.7 which is in the moderate range
- Interference that chronic pain causes on daily activities (0=No Interference to 10=Completely Interferes): Average of 4.3 – also in the moderate range
- 16% of the sample reported having Neuropathic Pain
- 76% report that pain occurs daily or is constant

Pain Locations

- In a sample of 1762 individuals with moderate to severe TBI and current chronic pain
- Median – **4 locations** (IQR 2-6)

Pain Locations	Current Pain (N = 1762)
Back	64.9%
Legs or Feet	60.8%
Shoulder	47.9%
Head	47.3%
Neck	44.9%
Arms or Hands	40.2%
Hips	35.6%
Face or Jaw	17.7%
Pelvic Area or Groin	15.8%
Buttocks	12.2%
Widespread Pain or Fibromyalgia	10.6%
Abdomen	10.2%
Chest	10.2%

Type of Headache

	Current Head Pain (N = 828, 47.3%)
Migraine	68.5%
Probable Migraine	12.5%
Tension Type	10.7%
Cervicogenic	1.2%
Unclassifiable	7.0%

Treatments Utilized

Treatment History Characteristics	Current Pain (N = 1763)
Total Medical Services or Treatments	**93.7%**
Medication	91.2%
Injection	31.7%
Surgery	17.5%
Implanted Device	3.1%
Non-Implanted Electrical Stimulator	27.5%
Other	11.2%
Total Exercise Therapies	**81.5%**
Physical Therapy	67.2%
Pool or Aquatic Therapy	26.9%
Occupational Therapy	39.0%
Yoga	23.9%
Tai Chi	5.4%
Home Exercise Program	62.2%
Other	7.1%

Treatments Utilized (cont'd)

Treatment History Characteristics	Current Pain (N = 1763)
Total Psychological Services	**43.8%**
Deep Breathing	35.3%
Mindfulness Therapy	19.5%
Psychotherapy (e.g., CBT, ACT)	17.8%
Guided Imagery	11.6%
Biofeedback	6.3%
Hypnotherapy	2.6%
Other	3.7%
Total Complementary/Alternative Medicine	**57.6%**
Massage	45.9%
Chiropractic	31.5%
Acupuncture	20.8%
Other	11.0%
Comprehensive Pain Rehabilitation Program	**14.6%**

Comorbid Psychosocial Conditions

	Current Pain	No Pain
Depression (PHQ-9), Mean (SD)	8.0 (6.2)	3.3 (4.1)
Anxiety (GAD-7), Mean (SD)	6.5 (5.8)	2.5 (3.8)
Post-Traumatic Stress Symptoms (PCL-5), Mean (SD)	22.9 (17.9)	9.1 (11.4)
Life Satisfaction (SWLS), Mean (SD)	20.4 (8.2)	24.4 (7.4)
Sleep Quality (PSQI), Mean (SD)	8.6 (4.6)	4.8 (3.5)
Participation (PART-O), Mean (SD)	1.7 (0.7)	2.0 (0.7)

How the use of extreme phenotypes can help us study pain and the impact of treatment

What is extreme phenotyping?

- Goal is to identify individuals with TBI who fall at extreme ends (best and worst) in order to see which characteristics differ between them.
- This approach has been used in diseases such as cancer and HIV to identify targets for treatment.
- Shifts from only trying to understand cause, to considering multiple variables which may lead to targeting or developing treatments that work.

What is the potential benefit?

Identifying extreme phenotypes, such as demographic, individual, and treatment factors associated with those who have chronic pain but have minimal interference compared to those who are significantly impacted by pain, will allow us to identify treatment targets (behavioral, cognitive, biological, and molecular) to advance a personalized medicine approach to treatment unlike any approach in TBI and chronic pain to date.

Extreme groups may provide suggestions for ways to examine the impact of treatment. For example:

- When pain interference was the outcome, pain characteristics were important to distinguish high vs. low interference groups. For example, the high interference group had higher pain intensity, neuropathic pain, migraine, or higher catastrophizing.
- When improvement from treatment was the outcome, characteristics of the individual were important for treatment responsiveness. For example, the high improvement group was more likely to be female, married, and have lower pain intensity and lower frequency of pain.
- We also examined how extreme phenotypes interacted with psychosocial conditions and found that those in the worse groups also had worse psychosocial outcomes, but all were significantly impacted by pain intensity.

Summary

Chronic pain is a significant problem across all years following TBI and is complicated!

- There are many different causes of pain and pain problems
- Many different treatments are utilized, but people *still* have chronic pain

There is also significant variability within those who are ***currently*** experiencing chronic pain.

- The Pain Interference extreme phenotype appears to be more influenced by one's experience of pain
- The Perceived Improvement extreme phenotype appears to be more influenced by receipt of treatment
- Both are impacted by pain severity

Assessing and treating chronic pain for individuals with TBI is essential to improve quality of life and other psychosocial outcomes.

Identify facilitators and barriers to evidence-based chronic pain treatments for persons with TBI

J Head Trauma Rehabil
Vol. 39, No. 1, pp. E1–E14

Provider Perceived Facilitators and Barriers to Identifying, Perceiving, and Seeking Healthcare for Chronic Pain After TBI: A Qualitative NIDILRR and VA TBI Model Systems Collaborative Project

J Head Trauma Rehabil
Vol. 39, No. 1, pp. E15–E28

Provider Perspectives of Facilitators and Barriers to Reaching and Utilizing Chronic Pain Healthcare for Persons With Traumatic Brain Injury: A Qualitative NIDILRR and VA TBI Model Systems Collaborative Project

J Head Trauma Rehabil
Vol. 39, No. 1, pp. E29–E40

Stakeholder Engagement to Identify Implementation Strategies to Overcome Barriers to Delivering Chronic Pain Treatments: A NIDILRR and VA TBI Model Systems Collaborative Project

Design / Recruitment

Prospective qualitative study

- Individual interviews of current pain and TBI providers with convenience samples and snowball sampling (January 2020- June 2021)
- Inclusion Criteria: Currently practicing clinician who treats TBI/chronic pain in the United States with more than 2 years of experience
- Interviews transcribed, codebook developed, reliability agreement rate of 80% amongst 2 reviewers, coded using content analysis in ATLAS.ti v.8 to develop themes.

N = 63

- N = 28 Rehabilitation Therapists (OT, PT, SLP)
- N = 15 Psychologists
- N = 17 Nurses/Medical Doctors (MD, DO)
- N = 3 Resource Facilitators

- N = 37 Civilian Providers
- N = 25 VA Providers
- N = 1 DoD Provider

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Healthcare Access Framework

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Across Supply Dimensions

- **45 Facilitators (F)**
- **19 Barriers (B)**

More data on supply side as we interviewed providers only

Across Demand Dimensions

- **11 Facilitators**
- **11 Barriers**

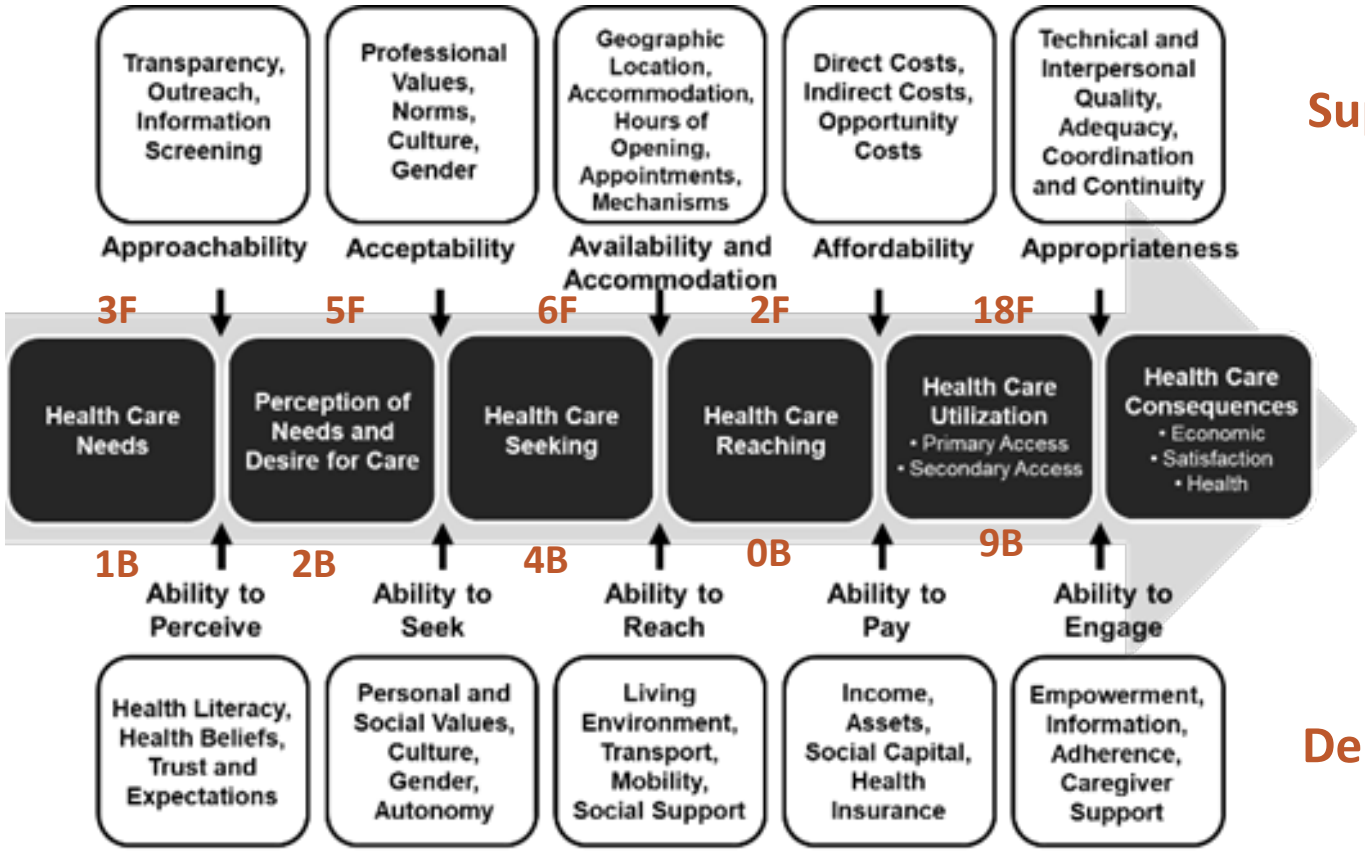

Figure 1. A Conceptual Framework for Accessing Chronic Care Needs

Supply Side

Demand Side

Overall Top Barrier Determinants (Themes) to Accessing Care

Theme: **Cognitive deficits of patients; 67% Saturation**

- **Healthcare Setting Difference:** Civilian (78%) vs VA (48%)
- **Provider Type Difference:** Medical (94%) vs Psychologists (67%) vs Rehabilitation Therapists (50%) Identified Theme

"Some of the challenges, particularly with TBI patients, are the cognitive considerations [to help] them remember to utilize strategies [if they] have the ability to learn and utilize new strategies for pain management…For some, difficulty learning [new] information or communication issues can be more challenging."

Overall Top Barrier Determinants (Themes) to Accessing Care

Theme: Patient comorbidities; 63% Saturation

- **Healthcare Setting Difference:** Civilian (81%) vs VA (36%)
- **Provider Type Difference:** Medical (76%) vs Psychologists (89%) vs Rehabilitation Therapists (46%)

I would say the biggest [challenge] is the patient who … already had chronic pain and [then] has a traumatic brain injury, sometimes the focus of their [pain] symptoms gets shifted to the brain injury for a period of time and things can even get attributed to that even if [the pain symptoms] were preexisting.

Theme: Patient participation (no show, don't follow up, non-compliant); 62% Saturation

- No subgroup differences observed

TBI patients unfortunately forget things; they're not as compliant because they don't remember. You [must] be cognizant of that when treating TBI patients. It's the patient population. You give them five or ten things to do, they [are] probably not going to do any of them."

Nakase-Richardson R, Cotner BA, Martin AM, Agtarap SD, Tweed A, Esterov D, O'Connor DR, Ching D, Haun JN, Hanks RA, Bergquist TF, Hammond FM, Zafonte RD, Hoffman JM. Provider Perspectives of Facilitators and Barriers to Reaching and Utilizing Chronic Pain Healthcare for Persons with Traumatic Brain Injury: A NIDILRR and VA TBI Model Systems Collaborative Project, *J Head Trauma Rehabil*; 39 (1), E15–E28.

Overall Top Facilitator Determinants (Themes) to Accessing Care

Ability to match treatment to patient needs; 100% Saturation

I look extensively at their [patient with TBI] history, looking for evidence of psychiatric care, past substance abuse issues, if they've been treated by physiatrists for pain issues. I see their inpatient physical therapy and outpatient clinic notes. When I interview the patient, I do standard review of their mental health histories. For pain, what medications have they tried, what other modalities besides medication? What is the level, nature, and presentation of pain? Looking for depression, anxiety, personality disorder, and cognitively (…presence of problem-solving deficits, difficulties with memory and information acquisition, attention, concentration), and I try to get a formulation of how the patient is understanding their pain.

Having multidisciplinary teams; 97% Saturation

The way the system works for us is that the pain center is a consult-only process. So, patients must get referred into the pain center by another provider. They meet with one of the physicians and then the physician determines [if] they should see OT, PT, chiropractic, rec therapy… And then we just collaborate from there. "The programs are very team-approach, they are interdisciplinary.

Having staff with specialized expertise to work with TBI; 95% Saturation

It is challenging to get comorbidities treated by providers who understand cognitive disability that come along with brain injury…finding a therapist who can take into consideration the cognitive limitations are hard to find."

Nakase-Richardson R, Cotner BA, Martin AM, Agtarap SD, Tweed A, Esterov D, O'Connor DR, Ching D, Haun JN, Hanks RA, Bergquist TF, Hammond FM, Zafonte RD, Hoffman JM. Provider Perspectives of Facilitators and Barriers to Reaching and Utilizing Chronic Pain Healthcare for Persons with Traumatic Brain Injury: A NIDILRR and VA TBI Model Systems Collaborative Project, *J Head Trauma Rehabil*; 39 (1), E15–E28.

Research Translation

J Head Trauma Rehabil
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Stakeholder Engagement to Identify Implementation Strategies to Overcome Barriers to Delivering Chronic Pain Treatments: A NIDILRR and VA TBI Model Systems Collaborative Project

TABLE 3 *Example of mapping matrix of objectives, theory/research basis, and implementation strategies for a prioritized barrier*

Prioritized barriers	Objectives	Theory/research basis	Implementation strategy
• Cognitive deficits of patients (67%) • Patient comorbidities (63%) • Patient participation (62%) • Mental health and/or substance abuse issues (59%)	Engage persons with TBI to validate and/or identify strategies to overcome barriers to accessing pain treatment, to promote uptake of tailored interventions and respond to their identified needs (eg, cognitive deficits, comorbidities, etc)	Principles of patient engagement and evidence-based practice to engage persons with TBI to identify their needs and inform tailored interventions[31,55]	Continue engagement efforts to validate and inform strategies and implementation efforts: • Intervene with patients/consumers to enhance uptake and adherence • Involve patients/consumers and family members • Obtain and use patients/consumers and family feedback • Prepare patients/consumers to be active participants
	Tailor pain interventions, treatment and delivery to be appropriate for persons with TBI, and their identified needs (eg, cognitive deficits, comorbidities, etc)	Principle of patient-centered care to adapt interventions, treatment and delivery to meet the individualized needs of the patient[56,57]	Tailor strategies: Employ evidence-based best practices and guidelines to inform tailored pain interventions, treatment and delivery to be appropriate for persons with TBI, and their identified needs (eg, cognitive deficits, comorbidities, etc)
	Adapt evidence-based policies, guidelines, and best practices to facilitate access for persons with TBI, and their identified needs (eg, cognitive deficits, comorbidities, etc), and disseminate to target audiences	Principle of health policy development to leverage evidence-based policies and guidelines to facilitate best practices in care[52–60,61]	Mandate change: Work with leadership to declare the priority of appropriate tailored pain treatment and delivery to be for persons with TBI and their identified needs (eg, cognitive deficits, comorbidities, etc)
	Increase awareness, skills, and readiness of workforce to deliver pain treatment to persons with TBI and their identified needs (eg, cognitive deficits, comorbidities, etc)	Evidence-based practice to increase workforce readiness through professional training and education[31,57]	Develop workforce readiness to deliver pain treatment to persons with TBI and their identified needs (eg, cognitive deficits, comorbidities, etc): • Conduct educational meetings • Conduct educational outreach visits • Conduct ongoing training • Create a learning collaborative • Develop educational materials • Distribute educational materials

Abbreviation: TBI, traumatic brain injury.

- ❑ **Engage Persons with Lived Experience to Overcome Barriers**
- ❑ **Tailor Strategies**
- ❑ **Mandate Change**
- ❑ **Develop Workforce Readiness**

Haun JN, Nakase-Richardson R, Cotner BA, Agtarap SD, Martin AM, Tweed A, Hanks RA, Wittine L, Bergquist TF, Hoffman JM. Stakeholder engagement to identify implementation strategies to overcome barriers to delivering chronic pain treatments: A NIDILRR and VA TBI Model Systems Collaborative Project, *J Head Trauma Rehabil*; 39 (1), E29–E40.

Objectives	Theory/Research Basis	Implementation Strategy
Engage persons with TBI to validate, and/or identify, strategies to overcome barriers to accessing pain treatment, to promote uptake of tailored interventions and respond to their identified needs (e.g., cognitive deficits, comorbidities, etc.).	Principles of patient engagement & evidence-based practice to engage persons with TBI to identify their needs and inform tailored interventions.	Continue engagement efforts to validate and inform strategies and implementation efforts: ○ Intervene with patients/consumers to enhance uptake & adherence ○ Involve patients/consumers and family members ○ Obtain and use patients/consumers and family feedback ○ Prepare patients/consumers to be active participants

Engage Persons with TBI Lived Experience

Haun JN, Nakase-Richardson R, Cotner BA, Agtarap SD, Martin AM, Tweed A, Hanks RA, Wittine L, Bergquist TF, Hoffman JM. Stakeholder engagement to identify implementation strategies to overcome barriers to delivering chronic pain treatments: A NIDILRR and VA TBI Model Systems Collaborative Project, *J Head Trauma Rehabil*; 39 (1), E29–E40.

OBJECTIVES	THEORY/RESEARCH BASIS	IMPLEMENTATION STRATEGY
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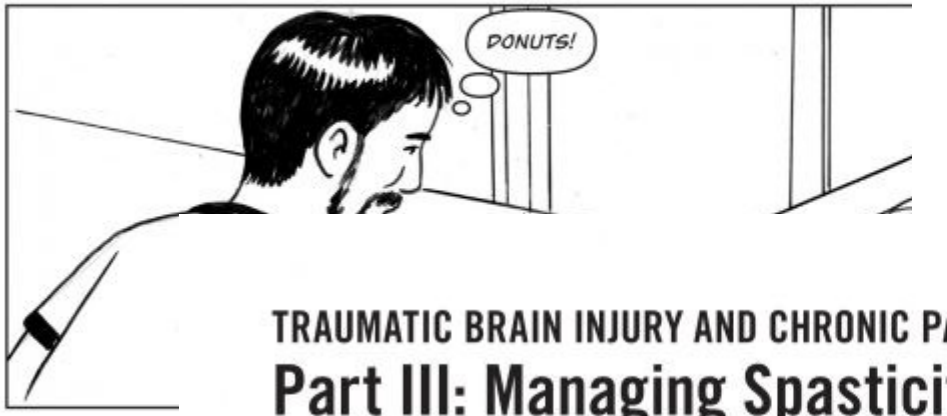
Develop Workforce Readiness

Haun JN, Nakase-Richardson R, Cotner BA, Agtarap SD, Martin AM, Tweed A, Hanks RA, Wittine L, Bergquist TF, Hoffman JM. Stakeholder engagement to identify implementation strategies to overcome barriers to delivering chronic pain treatments: A NIDILRR and VA TBI Model Systems Collaborative Project, *J Head Trauma Rehabil*; 39 (1), E29–E40.

TRAUMATIC BRAIN INJURY AND CHRONIC PAIN

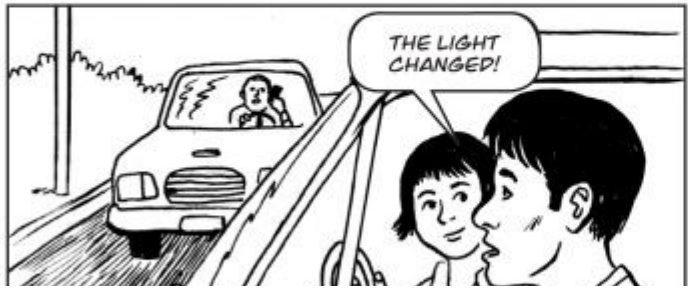
Part I: Life with Chronic Pain



TRAUMATIC BRAIN INJURY AND CHRONIC PAIN

Part II: Co-occuring Injury and Pain

Illustrations by: David Lasky and Tom Dougherty
Written by: Silas James and Ayla Jacob



TRAUMATIC BRAIN INJURY AND CHRONIC PA

Part III: Managing Spastici

TRAUMATIC BRAIN INJURY AND CHRONIC PAIN

Part IV: Pain and Anxiety

Illustrations by: David Lasky and Tom Dougherty
Written by: Silas James and Ayla Jacob

Pain and Anxiety

Anxiety is closely related to pain, and each can make the other worse. Anxiety can add to memory or sleep problems. Anxiety may lead a person to believe that a bad outcome is likely or certain. This type of thinking is called "catastrophizing".

Pain can change your thinking. Often, we have thoughts that we're not fully aware of called "automatic thoughts". They can influence our emotions and the things we do, even if we don't realize it. Pain by itself or with depression, anxiety or PTSD can make people have more negative automatic thoughts. These thoughts can make people do things that may make their pain worse. A therapist who practices cognitive behavioral therapy can help change these thinking patterns.

Check out our website:

pain.tbindsc.org

Read the Topical Issue from JHTR:

1. Hoffman, JM, Nakase-Richardson, R, Harrison-Felix, C (2024). Informing our understanding of chronic pain epidemiology, extreme outcomes, and healthcare access among persons with hospitalized TBI: A NIDILRR and VA TBI Model Systems collaborative project. Journal of Head Trauma Rehabilitation, 39(1), 1-4. PMID: 38167714
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