EARLY, EQUITABLE AND TRAUMA RESPONSIVE CARE FOR CHRONIC PAIN AND MENTAL HEALTH
ACKNOWLEDGEMENTS

Mental Health America (MHA), formerly the National Mental Health Association, was founded in 1909 and is the nation's leading community-based nonprofit dedicated to addressing the needs of those living with mental illness and promoting the overall mental health of all. Our work is driven by our commitment to promote mental health as a critical part of overall wellness, including prevention services for all, early identification and intervention for those at risk, integrated care and treatment for those who need them, with recovery as the goal.

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This report was researched, written and prepared by Madeline Reinert, Taylor Adams, Danielle Fritze, and Theresa Nguyen.
Chronic pain conditions such as osteoarthritis, lower back, and neck pain are consistently the leading causes of disability worldwide. Chronic pain affects up to 30 percent of people aged 18 to 39 years, and older individuals have an even higher prevalence of chronic pain.

Mental health conditions and chronic pain are comorbid conditions that often exacerbate one another. People can start to experience anxiety and fear in the anticipation of possible pain. For others, a mental health condition can trigger the onset of physical pain. Depression, anxiety, and fear about pain are linked to a higher probability of developing chronic pain and poor prognosis for recovery. Twenty to 50 percent of people with chronic pain also have depression. Even when the symptoms of depression improve, people with a history of depression are more at risk of chronic pain.

Mental Health America (MHA) is dedicated to understanding the specific experiences of people living with mental health and co-occurring chronic conditions in order to create better mental health resources and supports, and make changes to the ways care is provided to those who are struggling.

In 2014, MHA launched the program MHA Screening (www.mhascreening.org) where to date, over 6 million individuals have explored their mental health concerns using the ten clinically validated screens available for mental health conditions including depression, bipolar, anxiety, substance and alcohol use, psychosis, and post-traumatic stress disorder (PTSD). Between 2015 and 2019, 161,363 individuals who self-identified as living with arthritis or other chronic pain completed a mental health screen.

In 2019, MHA conducted an in-depth analysis of the intersection between mental health, arthritis, and chronic pain. Our sample size of users who took a mental health screen and identified as struggling with arthritis and chronic pain included 38,000 screeners. In this report, qualitative feedback was provided to the question “How can MHA help you?”

**Main Findings**

- People with arthritis or other chronic pain are more likely to screen positive or moderate to severe for a mental health condition (79 percent) than the general screening population.

- PTSD was the primary concern for screeners with chronic pain: 48 percent of people who took a PTSD screen and reported having a chronic health condition had chronic pain.

- Veterans and active duty military are the special population group most affected by arthritis or chronic pain: Over half (54 percent) who reported having a chronic health condition had arthritis or other chronic pain, followed by caregivers at 47 percent and trauma survivors at 46 percent.

- There is an unmet need among veterans and active duty military, caregivers and mothers with chronic pain: While veterans or active duty military members with arthritis or other chronic pain were more likely to have received treatment or support for a mental health condition in the past, 77 percent scored positive or moderate to severe for a mental health condition. Despite screening positive for a mental health condition, 30 percent of caregivers and 36 percent of new mothers had never received mental health treatment or support.

- Screeners with chronic pain were more likely to have received treatment or support for their mental health than those without chronic pain, although 36 percent reported never receiving any treatment or support, and over half (52 percent) who had in the past were no longer receiving it. Even among people with arthritis or chronic pain who screened positive or moderate to severe for a mental health condition, 40 percent had never been diagnosed.

- People with chronic pain are looking for treatment: 80 percent of screeners with chronic pain reported wanting to take next steps after screening, and 24 percent reported that they wanted to receive treatment. 48 percent of people with chronic pain are receiving treatment and still taking a screening for mental health conditions, indicating that their treatment is not sufficient to meet both their physical and mental health needs.
MHA has outlined several recommendations to better support people with chronic pain based on the findings.

- **Primary care physicians should initiate conversations about mental health and chronic pain.** It is important to be proactive about exploring these topics with patients rather than waiting for patients to report symptoms. Patients with arthritis or chronic pain should be screened for commonly co-occurring conditions such as PTSD, bipolar disorder, depression, and anxiety. Similarly, patients who report mental health conditions should be screened for pain.

- **Include behavioral health as a central feature of care for arthritis or other chronic pain.** Care should include a focus on trauma, stress, anxiety, depression, PTSD, coping skills, and resilience-building - as opposed to solely substance use-focused services and supports.

- **Engage in trauma-informed care for patients with chronic pain.** Trauma and chronic pain are strongly connected, and even when patients may not have a diagnosed mental health condition, their experience with trauma likely impacts their engagement with the health care system as well as pain management and treatment.

- **Ensure that care is patient-centered and includes the use of shared decision-making tools.** Effective care for people with arthritis or chronic pain and mental health conditions does not follow a one-size-fits-all approach, and the needs, goals and preferences of each individual patient must be recognized and included in the treatment plan.

- **Integrate peer support specialists, community health workers (CHW), and other paraprofessionals into care teams.** Having peer support specialists or CHWs who are representative of the patient populations creates better care. Peer staff can bring better understanding of the lived experience of trauma, mental health conditions and chronic pain.

- **Expand interdisciplinary, team-based and coordinated care.** Inclusion of behavioral health providers, paraprofessionals and caregivers on a care team allows for treatment of the whole patient, and provides greater support to the pain provider by including others they can consult for advice and resources, and utilize for specialty care if necessary. No one provider is responsible for every aspect of care for the patient.

- **Invest in more representative research for treatment and pain measurement tools that work for diverse populations.** Ensure that the findings of that research are built into medical school curricula. Pain is consistently undermeasured, underreported and underdiagnosed among BIPOC, LGBTQ+ and gender diverse communities. To eliminate disparities in care for arthritis and chronic pain, we must invest in pain research not solely focused on white, heterosexual and cisgender populations, and ensure that the findings from that research are taught to emerging medical professionals.
Studies have shown that the relationship between mental health conditions and pain is bidirectional, meaning the presence of one is associated with, and often exacerbates the experience of the other. For example, depression is a positive predictor of the development of chronic pain, and chronic pain increases the risk of developing depression. While heightened stress and anxiety increase the risk for and intensity of pain, greater pain in turn results in worsening psychosocial stress and factors that contribute to worsening physical health, such as greater social isolation, disruptions in sleep and reductions in positive health behaviors. This creates a cycle in which pain and mental health conditions continue to exacerbate one another. In addition, the stigma associated with chronic pain and mental health conditions, and the fact that both are “invisible illnesses,” or conditions that may not be outwardly visible to others, often cause both conditions to be minimized and undertreated.

Among patients with chronic pain, 35 to 45 percent experience depression. In a study of 18,980 subjects, 43.4 percent of people who met the criteria for major depressive disorder also met the criteria for chronic painful physical condition (CPPC), a percentage significantly higher than the 16.1 percent of the general population with CPPC. Patients with osteoarthritis (OA), the most common form of arthritis, have also been found to have higher odds of developing depression and suicidal ideation than those without OA. Patients experiencing both depression and pain sought 20 percent more initial visits to medical providers and had higher total medical costs compared to patients with depression without pain.

A complex relationship exists between regions in the brain associated with the emotional and sensory features of pain and regions affected by certain mental health conditions, which may increase pain intensity and disability for people with chronic pain. For example, for people with anxiety and depression, an exacerbation of physical pain is associated with decreased efficacy of pain treatment. Patients with depression may have greater emotional reactivity to pain, which makes it harder to regulate pain management options. Being preoccupied with pain has also been linked to the development of chronic pain. Positive outlooks and attitudes like optimism are associated with a greater ability to cope with pain and lower severity of pain. However, distress, anxiety, and negative attitudes are all linked to chronic pain.

People who experience adversity or emotional or physical trauma in childhood also have a higher risk of chronic pain in their adult lives. Fifty-five percent of people who have experienced multiple adverse childhood experiences (ACEs) have chronic pain. A study of children ages 9 to 19 with chronic pain found that the most common ACE in children with chronic pain is having a family member with mental illness.

In addition to trauma in children, a positive relationship exists between PTSD and chronic pain, including back pain, headaches, fibromyalgia, and arthritis. In a study of the prevalence of mood and anxiety disorders and arthritis in a nationally representative sample, PTSD showed the second strongest association with pain-related disability, following panic disorder, and patients with PTSD report more severe pain than persons without PTSD. For veterans, having both PTSD and chronic pain is highly prevalent. Because of the bidirectional relationship between mental health conditions and chronic pain and the effect that they have on pain management, it is imperative to address mental health as part of pain treatment. Pain treatment programs without a mental health component may limit a patient’s opportunity for success.

To better understand the experiences of people living with arthritis or other chronic pain and mental health conditions, MHA examined the screening results of 161,363 individuals experiencing both conditions between 2015 and 2019. The following findings reflect the results of those analyses.
Across all screens, individuals with chronic pain were more likely to screen positive or moderate to severe for a mental health condition. Seventy-nine percent of screeners who reported pain scored positive for a mental health condition, compared to the general population where 74 percent scored positive.

Women are more likely to experience several pain-related conditions than men, including osteoarthritis, the most common form of arthritis and a leading cause of disability in the United States. Historically, MHA Screening populations have skewed female, with an average of 74 percent identifying as female. In our population, 76 percent of people with arthritis or other chronic pain who screened for a mental health condition identified as female. In 2019, with a sample of 89,702 users who identified their gender and reported having a chronic health condition, 37 percent of females identified having pain and 32 percent of males identified they struggled with pain. Thirty-four percent who identified as another gender reported chronic pain.

Screeners who reported chronic pain were less diverse than MHA’s general screening population, with 75 percent identifying as white, compared to 60 percent in the general screening population. 36 percent of screeners identifying as more than one race, 31 percent of Black or African American screeners, 28 percent of Hispanic or Latino screeners and 18 percent of Asian or Pacific Islander screeners who reported having a chronic condition in 2019 reported that it was chronic pain, compared to 42 percent of White screeners. Prior research has shown racial disparities in reporting and diagnosis of chronic pain, particularly among Black and African American patients, which may contribute to the lack of diversity in the screening population with chronic pain. However, other communities of color are even less likely to report experiencing chronic pain in screening, indicating a possible need for more research in the pain experience among diverse communities, to ensure equitable diagnosis and treatment.

Pain increases across life span development. Older screeners were more likely to report that they experienced chronic pain. About 60 percent of screeners ages 65 and over who reported a health condition said they had chronic pain. However, chronic pain was also present among young screeners, with 17 percent of 11- to 17-year-olds and 26 percent of 18- to 24-year-olds reporting having chronic pain.
Roughly 40 percent of people across all income groups who reported having a chronic health condition indicated that it was arthritis or other chronic pain. However, screeners with arthritis or chronic pain had statistically significantly ($p < 0.001$) lower income than those without arthritis or chronic pain.
PTSD AND SPECIAL POPULATIONS

There is a strong bidirectional link between the experience of trauma and chronic pain. People who experience adversity or emotional or physical trauma in childhood have a higher risk of chronic pain in their adult lives. Overall trauma exposure, especially interpersonal trauma where a perpetrator intentionally harms the person, is also significantly related to pain and osteoarthritis, among other conditions.

Screeners with arthritis or other chronic pain were most likely to take a PTSD screen. Forty-eight percent of individuals who took the PTSD screen and reported having any health condition were reporting chronic pain. The PTSD screen was followed by the bipolar screen at 38 percent, and the anxiety screen at 37 percent.

People who reported having arthritis or chronic pain were more likely to screen positive or at risk across several mental health conditions. Screeners with chronic pain were more likely to screen for severe anxiety (54%), severe depression (47%) positive for bipolar (54%) and positive for PTSD (92%).
Among people with chronic pain who took a PTSD screen and identified with a special population, 77 percent identified as trauma survivors.

Trauma survivors who reported pain and took a PTSD screen were also more likely to screen positive for PTSD than the general pain population. Ninety-five percent of trauma survivors with pain scored positive for PTSD, compared to 84 percent who score positive for PTSD in the general population of screeners.

Among special populations, veterans or active duty military were most likely to report having chronic pain at 54 percent, followed by caregivers at 47 percent and trauma survivors at 46 percent. Special populations such as veterans or active duty military or new or expecting mothers who reported having chronic pain were more likely to screen positive for a mental health condition than those without chronic pain. Trauma survivors scored about the same.
Seventy-seven percent of veterans with chronic pain scored positive or moderate to severe for a mental health condition. Veterans overall were more likely to have received treatment in the past than the general population of screeners, and veterans or active duty military with chronic pain were 10 percent more likely to have received treatment or support than those without chronic pain.

Seventy-eight percent of caregivers and 81 percent of new or expecting mothers with chronic pain scored moderate to severe for a mental health condition. Despite screening positive for a mental health condition, 30 percent of caregivers and 36 percent of new mothers had never received mental health treatment or support.
Feedback from users indicate significant distress and a need for urgency in responding to patient needs. But the fear a patient feels in initiating support can prevent access to care. It is difficult for people experiencing mental health conditions to bring up their symptoms to a provider, especially when they are already receiving treatment for a chronic physical health condition. These responses indicate how important it is for a provider to explore and initiate conversation for patients to explore complexities related to both pain management and mental health needs.

**URGENT NEED FOR PAIN SUPPORT**

- I NEED REAL HELP AND TREATMENT TO END THE PAIN.
- MY CASE IS SEVERE... I’VE READ, EXERCISED, MEDITATED. I NEED SOMETHING TO WORK.
- HOW TO LIVE WITH CHRONIC PAIN.
- I AM A LICENSED [HEALTH CARE WORKER] HERE INJURED AND WITHOUT OPTIONS DESPITE AN EXCELLENT EDUCATION AND DESIRE TO GET WELL AND WORK AGAIN IN SOME USEFUL CAPACITY.

**FEAR OF DISCUSSING SYMPTOMS**

- …I’M SCARED TO TELL MY THERAPIST THE THINGS I THINK ABOUT.
- I ALREADY HAVE ENOUGH ISSUES AND FEEL UNCOMFORTABLE TALKING TO THE DOCTOR ABOUT OTHER ISSUES.
- I AM AFRAID TO DISCUSS MY SYMPTOMS.

**RECOMMENDATIONS FOR SCREENING, TRAUMA-INFORMED CARE AND PATIENT SUPPORT**

Recognition of the link between trauma, PTSD and chronic pain is crucial to providing effective treatment for pain. These links are especially important to consider in the wake of population-level traumatizing events, such as the COVID-19 pandemic or widespread police brutality and racial violence. Research has shown that intentional interpersonal trauma, in which a perpetrator intentionally acts to harm the victim, is even more related to pain than non-intentional trauma, such as accidents or illness.

Widespread exposure to intentional interpersonal trauma that Black, Indigenous and People of Color (BIPOC) experience both in-person and through media may contribute to higher rates of chronic pain and mental health conditions, including PTSD.

Because trauma and chronic pain are so strongly connected, adequate care and treatment for pain must be trauma informed. Chronic pain cannot be treated without attending to a patient’s mental health needs, including psychological supports for past trauma and treatment of PTSD. Screening for PTSD and adverse childhood experiences (ACEs) in adolescents and young adults can lead to early identification and intervention, which can prevent chronic pain later in life.

- Given the high rates of comorbidity, providers treating patients with chronic pain should explore past trauma history. Being prepared with local resources and referrals to address trauma and PTSD with patients will help facilitate whole health recovery.
Historically, more research on the needs of veterans has highlighted the need to explore pain and trauma in a clinical setting. MHA’s research also finds that people who are caregivers experience levels of stress that may contribute significantly to their risk for pain and mental health conditions.

- Providers who identify patients who are caregivers should explore trauma and pain as potential areas for treatment and support. Along with medical treatment options, providers can refer caregivers to local supportive services such as respite care, groups, or other emotional support.

Patients need pain support and feel fear or discomfort in discussing new symptoms with their providers. These experiences may prevent patients from being forthcoming about new or ongoing symptoms.

- Providers can ensure quality care by initiating conversations about changes in symptoms for pain and mental health rather than wait for a patient to initiate disclosure.

There are many different risk and mediating factors for chronic pain and for mental health conditions, and treatments for both conditions do not follow a one-size-fits-all approach. Not only are the same treatments not effective for everyone, people with chronic pain and mental health conditions at different stages of care also want different resources and interventions. Treatment that is effective for a new or expecting mother living with osteoarthritic pain and PTSD is likely different from effective treatment for a veteran living with chronic pain and depression.

- Effective pain management necessitates that care be person-centered and based on the needs and goals of the individual. Providers must use shared decision-making tools that are continuously updated with new evidence and treatment modalities so that patient’s values and preferences can be better taken into account in selecting treatment.
Federal-level pain management best practices explicitly include the use of psychological supports in pain treatment, and therefore nearly all people who identify with arthritis or chronic pain should indicate they have received some form of mental health supports before.

People with chronic pain were more likely to have been diagnosed and received treatment or support for a mental health condition in the past than MHA’s general screening population. Among our general population of screeners, 41 percent report past treatment. This is likely because of their increased interaction with the health care system, where they may have been screened for a mental health condition in the past. However, even among people with arthritis or chronic pain who screened positive or moderate to severe for a mental health condition, one in three had still never received any mental health treatment or support, and 40 percent had never been diagnosed with a mental health condition.

Among screeners with chronic pain who had received treatment in the past, over 50 percent of screeners with chronic pain report they are not currently receiving treatment for a mental health condition.
The lack of mental health treatment among screeners with arthritis or other chronic pain cannot be explained entirely by ambivalence toward receiving care. Among those who scored at risk for a mental health condition, 80 percent reported wanting to take next steps after screening. Twenty-four percent of all screeners with chronic pain reported that they wanted to receive treatment, and 32 percent reported they wanted to discuss their results with someone as a next step after screening.

When evaluating differences among screeners who had past treatment, had no treatment, or left answers blank, the data indicate a possible decrease in ambivalence towards treatment among those with past treatment. Individuals who reported they had received past treatment were less likely to report that they would take no action post screening (14%) as compared to those who had no treatment or left answers blank (20%) and were also more likely than the other two groups to report that they would seek treatment post screening (30% vs 28% and 25%).
Our data indicate gaps in care among people who have received treatment in the past and among those who are currently receiving treatment.

- Eighty-four percent of individuals who had previously but are no longer receiving treatment are taking a screen and scoring moderate to severe for a mental health condition.
- Eighty-four percent of people who are currently receiving treatment for their mental health concerns are also taking a screen and scoring severe for a mental health condition.

Additionally, 37 percent of people currently receiving treatment reported that they took a screen because their treatment works but something else is going on, and 25 percent reported that their treatment no longer works for them.

Screeners with arthritis or chronic pain cited specific barriers that hindered them from receiving care for their mental health. Two commonly reported barriers were a lack of access to providers who could address both physical and mental health conditions and difficulties with navigating the health care system.

**ACCESS TO PROVIDERS TO ADDRESS WHOLE HEALTH**

- "A PROVIDER WHO CAN HELP ME DETERMINE WHAT IS A MENTAL HEALTH AND/OR PHYSICAL HEALTH ISSUE AND THE BEST NATURAL OPTIONS TO TREAT IT AND WAYS TO BE ABLE TO DEAL WITH SYMPTOMS IN A WORK ENVIRONMENT SO I WILL BE ABLE TO HAVE A JOB."

- "I TRY TO BE COMPLETELY HONEST WITH [MY DOCTOR]. I STRONGLY FEEL I'M JUDGED AS A 'PILL SHOPPER' WHEN I'M TRYING TO BE HONEST."

- "I NEED MEDICARE-ACCEPTED TREATMENT PROGRAM THAT MAIN FOCUS IS TRAUMA, ANXIETY, DEPRESSION, AND CHRONIC PAIN-BASED, NOT ADDICTION-BASED."

- "AN ACTUAL PERSON TO TALK TO. I TRIED MY LOCAL SERVICES. IT WAS A LADY ON A COMPUTER SCREEN FOR TEN MINUTES THAT HAD MY FILE MIXED WITH ANOTHER PATIENT. THAT SCARED ME."

- "I GET THE MEDICINE I NEED, BUT I HAVE NO ONE TO REALLY TALK TO."

- "MY PHYSICAL MEDICAL CONDITIONS ARE FLAT OUT BEING IGNORED AND NOT BEING TAKEN INTO CONSIDERATION AS A SOURCE OF MY SYMPTOMS."

- "I JUST WANT TO KNOW IF I AM DEPRESSED CLINICALLY OR IF IT'S BECAUSE OF MY CHRONIC PAIN."
I NEED ASSISTANCE MANAGING MEDICAL PROVIDERS, MEDICATIONS, HEALTH INSURANCE, FOLLOWING UP ON THEM, ETC.

MY DOCTORS AREN’T CONSISTENT ABOUT ANYTHING. IT IS LIKE THEY DON’T EVEN TALK TO EACH OTHER…

I HAVE A HIGH LEVEL OF COMORBID DISORDERS THAT FEED INTO EACH OTHER AND OFTEN UNDERMINE EACH OTHER’S TREATMENTS, SO GETTING THE RIGHT DIAGNOSIS AND TREATMENT IS REALLY HARD. I’M NEVER SURE IF I’M ON THE RIGHT TRACK OR NOT.

RECOMMENDATION TO SCREEN REGULARLY DURING VISITS

Findings suggest that despite receiving care in the past or even currently receiving treatment, individuals are seeking guidance for mental health conditions. These results indicate possible relapse in prior mental health concerns, premature discontinuation in past care, or the presentation of new problems.

- Screening regularly for new issues during routine visits can support better care. Regular check-ins help to identify new problems, but more importantly it increases therapeutic alliance that can decrease shame and fear and help cultivate conversation towards better care.

SPOTLIGHT ON EXPANDING WORKFORCE TO SUPPORT INTEGRATED CARE

Nuances related to trauma, the needs of special populations like caregivers and veterans, and fear related to disclosure indicate the benefits of a team-based approach to care. At minimum, if a patient is fearful of disclosing to a medical provider, that patient might feel more comfortable with discussing issues with a peer support specialist. Integrating paraprofessionals, like peer support specialists or community health workers (CHWs), can create opportunities to build trust and engagement so that patients can disclose trauma. Peer support specialists also have lived experience of trauma, mental health conditions, and chronic pain which helps to facilitate dialogue that decreases fear and promotes engagement in care and positive outcomes.

Interdisciplinary teams and coordinated care models have been shown to be effective models for treating complex comorbid conditions. For these models to work, a provider benefits from access to sufficient knowledge and support to decrease concerns related to screening patients for mental health conditions.

By integrating mental health care and including mental health providers on a care team, providers can feel more confident in screening patients with chronic pain for mental health conditions, because they have access to behavioral health clinicians they can consult for advice and resources, and utilize for specialty care if more complicated issues arise.

Expanding team-based care also helps patients who are struggling to navigate the health care system. Because of the fragmentation of the health care system and the lack of coordination and communication between providers described by screeners above, patients with chronic pain and mental health conditions are forced to act as their own advocates and coordinators. For patients with several comorbid chronic conditions or for patients who are just beginning to experience the symptoms of a mental health condition and are yet to be diagnosed, figuring out which providers to go to, which conditions are related and how to make sense of multiple diagnoses and treatment plans across providers is incredibly difficult. Creating a care team, especially one that involves peers, CHWs and caregivers helps to remove some of the onus for communication and coordination from the patient themselves, providing support in managing care.
RECOMMENDATIONS FOR QUALITY RESEARCH AND TRANSLATION INTO PRACTICE

Twenty-five percent of people with chronic pain who were currently receiving mental health treatment indicated that their treatment wasn’t working and their mental health had worsened, and when asked what MHA could do to help, many of the responses were calls for better treatments to live with pain.

- Federal and state entities must invest in better treatments for arthritis, chronic pain and mental health conditions. This includes investing in better, more representative research to find treatments and develop better pain measurement tools that work for a diverse population, so BIPOC, LGBTQ+, gender diverse and other communities traditionally underrepresented in this research can be identified, diagnosed and treated more effectively and appropriately.

Research is meaningless unless it helps inform and is translated into practice. The most impactful opportunity to provide ubiquitous guidance on quality care is during medical school.

- Findings from research should be continuously integrated into medical school curriculum. A widely cited report from the National Academy of Sciences found that about half of medical students hold false beliefs about biological differences in pain between black and white patients, which leads to racial bias in pain recognition and treatment.12 Even as better research is conducted, it often takes years for medical school curriculum to be updated and amended. This curriculum must be continuously reexamined with a focus on reducing racial biases and inequities in care. This serves as a form of early intervention, whereas new providers enter practices with information that helps them to better serve a diverse U.S. population with a lens toward racial equity.
REFERENCES


