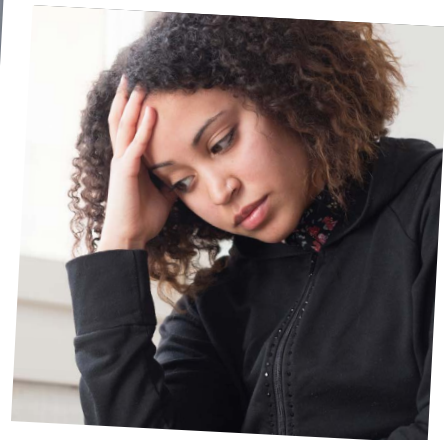


SCIENCE, INNOVATION AND
TECHNOLOGY SUMMIT:

Chronic Pain in Women— *Focus on Treatment, Management and Barriers*

Final Report



Pain is a very big deal.





PAIN DEFINED

Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. . . . Pain is always subjective. . . . It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience.”

– International Association for the Study of Pain, 1994

““ FINDING YOUR VOICE

Finding Your Voice, a special program at the close of Day 1, featured pain advocates who have coped with pain for much of their lives or serve as caregivers. Excerpts from the discussion about their lived experience with pain are highlighted throughout the report.

””

Table of Contents

EXECUTIVE SUMMARY	4
DAY ONE	
KEYNOTE PRESENTATION: Chronic Pain in Women: A Transformative Journey	6
OPEN PLENARY: Sex, Pain and Death	7
SESSION 1. RESEARCH ADVANCES AND INNOVATIONS IN TREATMENT	
■ Individual Differences in Pain Perception: The Need for a Personalized Approach	8
■ Molecular Mechanisms of Chronic Pain With a Focus on Migraine	9
■ Unmet Needs and Emerging Drugs for Chronic Pain	10
■ Technological Advances in Chronic Pain	11
SESSION 2. MANAGEMENT AND PREVENTION STRATEGIES	
■ Application of Behavioral Strategies and Interventions for Pain Control	12
■ Evidence-Based Efficacy of Noninvasive Nonpharmacological Approaches and Their Effectiveness in Treating and Managing Chronic Pain	13
■ Role of a Strategist to Help Patients Improve Pain and Overcome Daily Frustrations	14
■ Importance of Self-Management in Chronic Pain	15
SESSION 3. BARRIERS AND CHALLENGES IN PAIN TREATMENT AND MANAGEMENT	
■ Barriers to Providing Integrative Pain Care	16
■ Challenges to Pain Treatment Unique to Women	17
■ Challenges Pregnant Women Face With Opioids—Gender Differences in Pain and Substance Use Disorders	18
■ Overcoming Health Care Challenges: Maneuvering Through Communication, Access and Cost Barriers While Dealing With Chronic Pain	19
UPDATES FROM THE FEDERAL OFFICES OF WOMEN'S HEALTH	20
DAY TWO	
KEYNOTE PRESENTATION: Bias Against Women in the Treatment of Pain	21
OPEN PLENARY: Racial and Ethnic Disparities, Lived Pain Experiences and Stigma	22
SESSION 4. EFFORTS TO ADDRESS BARRIERS IN CHRONIC PAIN TREATMENT	
■ Implementing the National Pain Strategy at the State Level to Improve Education About and Treatment of Chronic Pain	23
■ Opioid Addiction in Women: Short- and Long-Term Implications	24
■ Breakthrough Solutions for Pain and Opioid Care	25
■ The Patient Voice in Pain and Development of Pain Therapeutics	26
SESSION 5. BRING ABOUT CHANGE THROUGH POLICY	
■ Addressing the Role of Federal Government Policies in Pain Management and Research	27
BUILDING A ROADMAP TO BEST PRACTICES FOR CHRONIC PAIN TREATMENT AND MANAGEMENT:	
■ Challenges and Opportunities for the Chronic Pain Community	28
CLOSING PLENARY: Pain, Resilience and How We Heal	30
APPENDIX 1: Agenda and Acknowledgements	32
APPENDIX 2: HealthyWomen's Chronic Pain Survey Executive Summary	34
REFERENCES	35



Executive Summary

“Pain is a very big deal. It can kill you.”

– Jeffrey Mogil, PhD, professor of psychology, McGill University

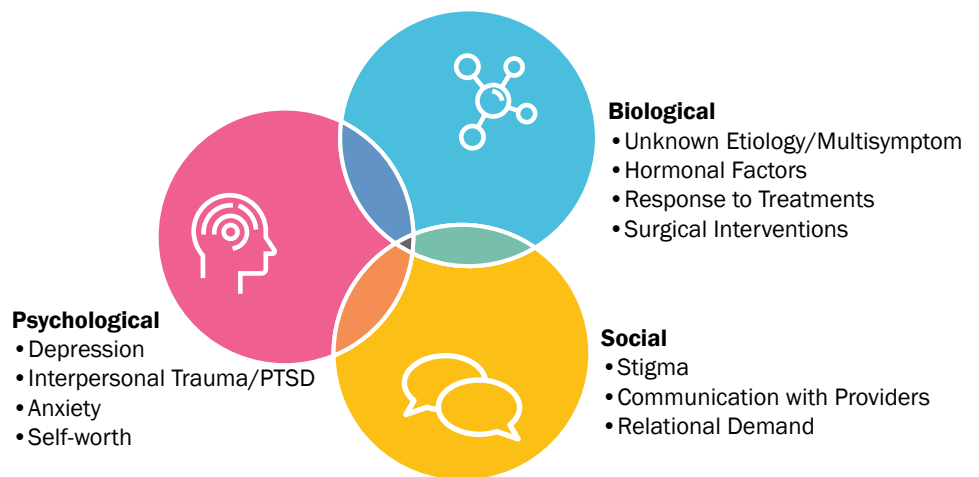
Chronic pain affects an estimated 100 million Americans, more than the total number who have been diagnosed with diabetes, cancer and heart disease combined. The cost is astronomical: \$630 billion, nearly as high as the U.S. Department of Defense budget.¹

The majority of those living with chronic pain are women, with an estimated 50 million or more women affected than men. Women are particularly vulnerable given the plethora of pain-related conditions that only occur in women, such as endometriosis, interstitial cystitis and vulvodynia, among others. But they are also significantly more likely than men to experience other pain-related conditions, including chronic fatigue syndrome, fibromyalgia, temporomandibular disorders, osteoarthritis, rheumatoid arthritis and migraine. Women are also more likely than men to have more than one pain condition at a time. Yet, women’s pain is too often misdiagnosed, minimized and under- or inappropriately treated.¹

The literature is rich with descriptions of sex-related differences in women’s response to pain and pain medications. For instance, studies find that women get greater pain relief from opioids than men but experience more side effects.² They also appear to process pain in the central nervous system differently than men.³

Treating women’s pain is complicated by the heterogenous contributors to the condition. The biopsychosocial model of pain highlights this challenge. (Figure 1.)

Figure 1: Applying a Biopsychosocial Model to Pain Treatment and Management Among Women



Despite overwhelming evidence of sex-related differences when it comes to chronic pain experience and treatment, this knowledge has yet to be integrated into clinical practice or fully embraced in clinical trials or even basic research.

In July 2019, HealthyWomen convened a two-day, multi-stakeholder meeting to identify knowledge gaps and challenges in treating and managing chronic pain in women: **Science, Innovation and Technology Summit: Chronic Pain in Women—Focus on Treatment, Management and Barriers**. The goal was to advance and elevate the current dialogue on effectively treating and managing chronic pain in women by addressing the numerous disparities, sex differences and stigma associated with chronic pain in women. Clinical professionals, researchers and policymakers, as well as representatives from federal agencies, industry, nonprofit organizations and advocacy groups attended, including several women who have been living with chronic pain for decades.

The objectives of the summit were to:

- Educate stakeholders about gaps in knowledge and research, policy and practice related to pain management in women.
- Identify key strategies for addressing these gaps.
- Begin to build a roadmap of best practices in the area of pain management for women.
- Address barriers to care that women and their caregivers experience.
- Identify potential partnerships and collaborative projects to improve the quality of care provided to women living with chronic pain.

HealthyWomen Chronic Pain Survey

In preparation for this summit, HealthyWomen surveyed 1,004 women with chronic pain about the effect of pain on their quality of life. Nearly all surveyed (95 percent) reported that pain impacted their ability to live a full life. More than half (52 percent) said that pain interfered with their sleep, and more than a third said that they felt hopeless about their pain and inadequately treated by their providers.

In addition, nearly 40 percent of those surveyed reported challenges accessing care, finding information, scheduling appointments and navigating complex health care systems in order to deal with their pain-related conditions.⁴

The resulting presentations and discussions are highlighted in this report. Key findings and recommendations included the need for:

- Comprehensive education of physicians and other health care providers, as well as the general public and patients, about chronic pain in women.
- Efforts to reduce the stigma surrounding chronic pain.
- Greater integration of sex and gender differences into pain research and clinical practice.
- Greater understanding of the psychosocial aspects of pain in women, including coexisting mental health conditions and past history of violence and abuse.
- Increased understanding of sex and gender differences in response to pain medications.
- Improved inpatient and outpatient addiction treatment for women that recognizes their unique needs, including pregnancy and caregiving.
- Efforts to address racial and sex disparity.
- Improved methods of assessing pain.
- Greater access to pain specialists and integrative approaches to pain management, including payer coverage.
- Multidisciplinary approaches and multi-treatment modalities for treating pain in women.

“It is central to the unique issues women face in pain management to understand the differences between men and women with respect to pain sensitivity, response to pain medication and predisposition to clinical pain conditions.”

– Draft Report on Pain Management Best Practices: Updates, Gaps, Inconsistencies and Recommendations. U.S. Department of Health and Human Services

KEYNOTE PRESENTATION

Chronic Pain in Women: A Transformative Journey

Anita Gupta, DO, PharmD, MPP

Professor, Rowan University School of Medicine

Senior Vice President, Heron Therapeutics

We must consider the unintended consequences of not considering sex and gender in medicine and research.

– Anita Gupta, DO, PharmD, MPP, Professor, Rowan University School of Medicine

Dr. Gupta's own experience with a rare medical condition and the pain it engendered forever changed how she interacted with her patients, she said. "I had spent years managing individuals who were experiencing chronic pain, I had taught medical students to assess and manage pain in others, and while I always took a compassionate approach, I have to tell you, it is much, much different when you're faced with your own health crisis."

"I truly became a doctor once I became a patient."

The experience also taught her that the primary tenet of treating pain is a human-to-human, compassionate connection.

She then turned her attention to gender-related issues in pain, noting growing evidence that the biological pathway for female pain differs from males and is a root cause of the variations seen in women's response to pain medications.

Other gender-related issues include the under-recognition of opioid overdoses in women, particularly since women's roles as caregivers make it difficult to seek or complete treatment, and differences in how doctors respond to women in pain compared to men. "I had women come to me in my pain clinic because they were seen by multiple male physicians and they were looking for a female opinion from a female physician."

Despite the variety of effective treatments and physicians who specialize in treating pain, women suffer unnecessarily from conditions such as back pain, postsurgical pain and cancer pain. "It's not because they're not being treated," she said. "It's because they're not receiving the right treatment."

"If females and males don't define and respond to pain the same way, should we be managing it the same way?"

We must factor the whole women into our development of pain treatments and how we use existing treatments," she said. "We must give women equal assessment of the right treatment for their pain. We need to transform and begin to identify which women are actually at risk for uncontrolled pain and chronic pain.

I'm here to tell you that women are due for a pain-relief payday."

THE PATIENT RESPONSIBILITY

Dr. Gupta listed four things people with chronic pain conditions should do:

- **Take charge of your health.** "I always tell my patients, empower yourself." Be active, be engaged with your pain, with your doctors, with anyone who is willing to listen.
- **Be positive.** Don't let stigma, negative energy or anyone pull you down. Positive thinking is a powerful tool to overcome health circumstances.
- **Reduce stressors in life.** Learning how to deal with stress in healthy ways can position anyone to cope more effectively with chronic pain.
- **Find an advocate.** Reach out to others who are in the same position, such as through a support group or organization, who can understand your highs and lows.

Sex, Pain and Death

Jeffrey Mogil, PhD

Professor of Psychology, McGill University



Dr. Mogil opened his talk with a brief explanation of the importance of pain: to avoid or minimize tissue damage. Such acute pain is explainable, as is tonic pain, in which pain lasts for hours and days for the injury to heal. “But what about chronic pain that lasts for months to years to potentially the rest of your life?” he asked. “That’s the great clinical problem that we’ve all been trying to study and treat for a long time, and, frankly, we’re not doing very well.

The treatment of chronic pain is inconsistent at best, works in only a minority of pain sufferers at any one time; is associated with terrible side effects, and hasn’t changed much in a long time.” In fact, he said, the only new thing in pain research in the last century is the chance discovery that certain antidepressants and antiepileptic drugs are effective in chronic pain.

“It is a major problem that we can’t do something about what is, in fact, the most important clinical problem we have,” Dr. Mogil said. (Figure 2.)

In addition, “It doesn’t matter how you measure it, and it doesn’t matter what type of pain you’re measuring, women are more sensitive to pain than men.”⁶

And yet pain-related research has not taken that into account. As late as 2015, he said, 80 percent of studies published in the flagship journal in the field, *Pain*, featured male rats or mice only in their studies. “That, of course, is unacceptable and it leads to problems in the literature.”

However, the NIH Policy on the Inclusion of Women in Clinical Research, which addressed sex as a biological variable (SABV), implemented in 2016, requires that scientists use both female and males animals and cell lines in their research. “Since then, the floodgates have opened and all kinds of people who are now using female animals for the first time are finding big, robust sex differences,” he said.

For instance, his group discovered that spinal cord cells called microglia, thought to play an important role in chronic pain overall, are only important in male animals.

In female animals, immune cells called T cells are critical.

“When it comes to pain processing, the neural circuits in male and female rats, mice and, presumably, humans, is proving to be more sexually dimorphic than anyone would have guessed,” Dr. Mogil said.

And that, he added, will likely lead to pain drugs that work in one gender but not the other.

He closed by noting that he is more optimistic about the state of pain research today than in a long time. Improvements in pain measurement in humans and animals; a greater understanding of the molecular contents of cells; the ability to activate

and isolate and study individual cells with technology such as optogenetics; artificial intelligence; and the potential of gene editing technologies like CRISPR; all have the potential to dramatically change the pain research field.

Dr. Mogil ended his presentation with a quote from Albert Schweitzer to emphasize his point: “Pain is a more terrible lord of mankind than even death itself.”

“This has always been true,” said Dr. Mogil. “It continues to be true, and, hopefully, one of these days soon, we’re going to be able to change the status quo.”

Figure 2: Pain Is the Most Important Clinical Problem

TOP 10 REASONS TO VISIT DOCTOR	TOP 10 MOST PREVALENT DISEASE GROUPS	TOP 10 CAUSES OF “YEARS LIVED WITH DISABILITY”
<ol style="list-style-type: none"> 1. Cough 2. Back pain 🤢 3. Abdominal pain 🤢 4. Sore throat 🤢 5. Dermatitis (itch) 6. Fever 7. Headache 🤢 8. Leg pain 🤢 9. Respiratory 10. Fatigue <p>(Finlay et al., <i>Can Fam Physic</i>, 2018)</p>	<ol style="list-style-type: none"> 1. Skin disorders 2. Osteoarthritis and joint disorders 🤢 3. Back problems 🤢 4. Disorders of lipid metabolism 5. Upper respiratory disease 6. Anxiety and depression 7. Chronic neurologic disorders 8. Hypertension 9. Headaches (including migraine) 🤢 10. Diabetes <p>(St. Sauver et al., <i>Mayo Clin Proc</i>, 2013)</p>	<ol style="list-style-type: none"> 1. Back pain 🤢 2. Headaches 🤢 3. Depression 4. Diabetes 5. Musculoskeletal disorders 🤢 6. Neck pain 🤢 7. Hard-of-hearing 8. Blindness 9. Anxiety 10. Drug abuse <p>(World Health Organization, Global Burden of Disease Initiative, 2017)</p>

The solution to understanding pain, he said, is to understand individual differences in pain. For instance, studies find individuals react differently to the same pain stimulus differently. In addition, most people don’t develop chronic pain after a pain-related injury or disease. The question then, he said, is why some people do.

Another question is why 70 percent of chronic pain patients are women. Women not only suffer from more pain-related disorders, Dr. Mogil noted, but the disorders themselves are more common than pain-related disorders in men.⁵

Individual Differences in Pain Perception: The Need for a Personalized Approach

Roger Fillingim, PhD

Distinguished Professor, University of Florida

“We have to consider individual differences if we’re going to adequately personalize pain treatment.”

– Roger Fillingim, PhD

One person’s pain is, well, one person’s pain.

That was the message from Roger Fillingim, PhD, who directs the Pain Research & Intervention Center of Excellence at the University of Florida in Gainesville. He highlighted a study showing pain scores in 150 patients six hours after laparoscopic gallbladder removal. While the median pain score was about a 50 out of 100, scores were widely divergent, with some patients reporting no pain and some rating their pain as 100.⁷

“This is not the exception,” Dr. Fillingim said. “This is the rule in pain. Robust individual differences exist in response to pain.”

Other numerous factors can affect pain sensitivity. For instance, the patients’ postsurgical pain could have been influenced by how serious their disease was before surgery; how the surgeon operated; and the effect of any pain medications, he said.

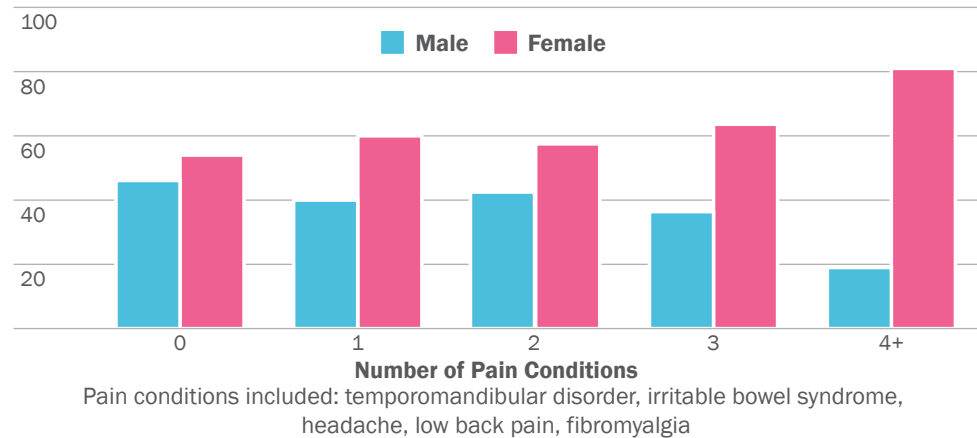
However, studies using the same pain stimulus demonstrate similar results. In one study of more than 300 healthy young adults who underwent a heat stimulus, each individual rated their pain differently on a scale of 1 to 100, noting significant differences between how participants rated their pain to the same stimulus.⁸

Those variations are particularly apparent when it comes to gender, with significant differences in how women perceive pain versus men. “Not only are women at greater risk for pain than men,” Dr. Fillingim said, “but women also have a higher risk of having multiple pain-related conditions.” (Figure 3).

KEY POINT

A better understanding of the factors that influence pain perception in women and men will help in the quest to develop personalized medicine approaches to pain.

Figure 3: Proportion of Females and Males by Number of Pain Conditions



Slade GD, Greenspan JD, Fillingim RB, Maixner W, Sharma S, Ohrbach R. Overlap of 5 chronic pain conditions: temporomandibular disorder, headache, back pain, irritable bowel syndrome and fibromyalgia. *J Oral Facial Pain H*, in press

UNDERSTANDING THE CLINICAL IMPLICATIONS OF SEX DIFFERENCES

“Improving the quality of pain-related care women receive and preventing the development of chronic pain requires understanding the sex specificity of pain-related factors if we’re going to design treatments to address those factors and target them to the right people,” he said.

Which leads to another question: Why do existing treatments work differently in women and in men? There are a couple of clues, both related to gene polymorphisms, according to Dr. Fillingim.

- The mu opioid receptor gene.** This gene contains the instructions for making mu opioid receptors, upon which exogenous and endogenous opioids work. A rare polymorphism in the gene changes pain responses. Interestingly, men with the mutation are less sensitive to pain, while women are more sensitive.⁹ Thus, a drug to target this gene would have opposite effects in men and women.
- The melanocortin-1 receptor gene (Mc1r).** Women with variants in the “redheaded” gene (so called because 80 percent of natural redheads express this gene) receive significantly more pain relief from the opioid pentazocine, which acts upon κ -opioid receptors, than women without the genetic variant. Men with the variants, however, demonstrate no difference in pain relief.¹⁰

Molecular Mechanisms of Chronic Pain With a Focus on Migraine

Gregory Dussor, PhD

Associate Professor, University of Texas

Dr. Dussor took participants on a journey through the molecular underpinnings of migraine, beginning with the source: the meninges that cover the skull. The pain of migraine, he said, is thought to come from the stimulation of nerve fibers in the meninges, signaling through trigeminal ganglia neurons.

What’s not clear, he said, is what activates those nerve fibers.

Dr. Dussor’s laboratory has focused on the acid-sensing ion channel (ASIC) protein, a receptor on the surface of nerve fibers that is sensitive to pH (a measure of the level of acidity that exists outside of the cell).

Their theory is that neurons that supply the nerves to the meninges express ASICs. Animal studies find that applying a low pH stimulus to meninges results in a drop in the pain threshold, causing body-wide hypersensitivity to touch, he said.¹¹

His team is also exploring the role of interleukin 6 (IL-6), an inflammatory cytokine. When applied to the meninges in animal studies, it, like the low pH stimulus, causes a “headache-like” response.¹²

They also learned that “priming” an animal to a stimulus like IL-6 hypersensitizes it to a second stimulus, like stress. All of which raises the question: “Are there certain kinds of receptors that you can go after in this phase after the animals have recovered from the first stimulus, but before you give them the second one? That might be a good therapeutic window for some novel strategy.”

Dr. Dussor and others in the pain field are also looking at a molecule called brain-derived neurotrophic factor (BDNF) to see if blocking BDNF receptors could “turn off” priming and prevent that response to a second stimulus.¹³

All of which leads back to migraine, which is not only

more common in women, but more disabling. New drugs target calcitonin gene-related peptide (CGRP), a protein released around the brain that causes extensive inflammation in the meninges. Interestingly, in an animal study Dr. Dussor and his team conducted, applying CGRP to the meninges triggered a response in female animals but no response in males indicating females are more susceptible to inflammation of the meninges. The females were also primed for a response to a second stimulus, but not the males. They found that priming female animals with IL-6, letting them recover, then giving them a very low dose of CGRP made them more sensitive to pain and led to more inflammation, a reaction that did not occur with men.¹⁴ “There clearly is a robust difference between males and females in what CGRP is doing,” he said.

“Although the recent approval of CGRP-based therapeutics is a major accomplishment, those therapeutics are not a ‘cure’ for migraine,” Dr. Dussor said. “Additional therapeutics are still necessary.”

KEY POINT

Biological mechanisms contribute to sex-specific differences in pain response in men and women. Drugs that target these molecular pathways could provide new options for pain management.

Potential Biological Mechanisms to Explore for Novel Migraine Treatments

- Acid-sensing ion channel proteins are a potential target for new migraine therapeutics.
- Mechanisms contributing to “priming,” including those related to brain-derived neurotrophic factor, should be further investigated.
- Further investigation of mechanisms mediating differential effects of calcitonin gene-related peptide (CGRP) in females and males may provide insight into the female-biased nature of migraine.
- Prolactin may be a contributing factor to migraine, but this is more likely in females.
- Although the recent approval of CGRP-based therapeutics is a major accomplishment, those therapeutics are not a “cure” for migraine. Additional therapeutics are still necessary.

Unmet Needs and Emerging Drugs for Chronic Pain

Srinivasa Raja, MD

Director of Pain Research, Johns Hopkins Blaustein Pain Treatment Center

Dr. Raja delivered a clear message in his talk: Today's drug therapies either have limited efficacy or are limited by adverse effects. Not to mention that few drug trials for pain have been conducted in women. Another key point: Don't assume that pain medications work similarly in women and men.

He highlighted a Swedish study underscoring what we know about sex differences in pain, that while men and women experience the same pain severity, women reported higher activity levels, pain acceptance and social support than men, while men seem to have higher mood disturbances, fear of movement and lower activity levels. The message? "Women seem to be coping with their pain much better than men."¹⁵

He also discussed the role of calcitonin gene-related peptide (CGRP) as a target for pain medications. The new CGRP inhibitors can reduce migraine days by about half in about half of those who use them, but they have to be injected. Oral CGRP antagonists under investigation demonstrate efficacy in both preventing as well as treating acute migraine attacks with minimal adverse effects.

"So, there is hope," he said.

Another pain condition that is very common in women is osteoarthritis, with the incidence in women rising much faster with age than in men. Current treatments such as exercise, weight loss, nonsteroidal anti-inflammatory drugs (NSAIDs) or acetaminophen, are not very effective in later stages of osteoarthritis, leaving few treatment options.

KEY POINT

Drug therapies for chronic pain have limited efficacy and safety, particularly for women. New approaches are needed.

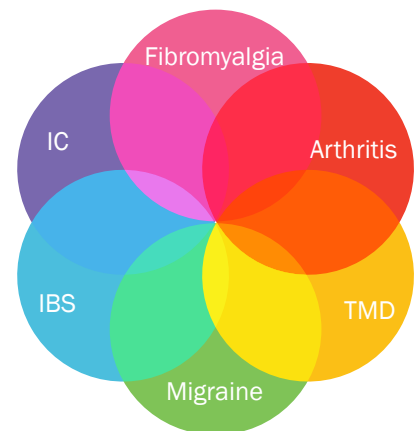
Today's focus is on disease-modifying drugs for osteoarthritis that target the underlying molecular pathways inherent in the disease. "Understanding that osteoarthritis is more complex than just a cartilage disease has led to research along the etiologies, that is, drugs or strategies that may promote cartilage growth and repair, or drugs that may affect controlling inflammation," Dr. Raja said.

Chronic Pain in Women With Overlapping Pain Conditions

Some common pain conditions

(2-3 times more prevalent in women than men)

- Fibromyalgia
- Arthritis: Rheumatoid, Osteo
- Orofacial Pain
 - Migraine headache
 - Temporomandibular disorders (TMD)
- Visceral and Pelvic Pain
 - Irritable bowel syndrome (IBS)
 - Interstitial cystitis (IC)



FINDING YOUR VOICE

"I lost all of my independence. We live with social isolation, which is by far the worst part of the chronic pain experience for us. I live every moment of my life with severe pain and fatigue, and I now have 10 comorbidities."

– **Cynthia Toussaint**, diagnosed with complex regional pain syndrome after a minor ballet injury. She is co-founder of the advocacy organization For Grace.



Technological Advances in Chronic Pain

Julie Pilitsis, MD, PhD

Professor of Neurosurgery, Albany Medical College

Dr. Pilitsis moved the discussion away from pharmacological therapies for pain-to-pain modulation devices. By the time patients turn to these approaches, she said, they have typically failed everything else, including medications, surgery, injections and physical therapy, among other interventions.

Spinal cord stimulation, in which an electric device is placed in the epidural area of the spine and connected to a battery, similar to a pacemaker, is one of the oldest such technologies, used successfully for people with back pain and complex regional pain syndrome for decades. It works by distracting the brain from the painful stimulus by providing a different stimulus. Studies find that about half of those on neuromodulation report a 50 percent reduction in their pain at about two years.¹⁶

In her own clinical practice, Dr. Pilitsis finds that about 72 percent of her patients get pain relief from neuromodulation. She attributes that to the multidisciplinary team of professionals who provide holistic care and advocate for the patient. “When you’re in that kind of environment, it reduces your stress, it reduces your anxiety and you tend to do better,” she said.

She also found that women are slightly more likely than men to ask to have the devices removed (10 percent versus 7 percent). The main reason for the difference, she said, is that more women were losing benefit and experiencing pain at the insertion site than men. She also found higher rates of depression in women one year after the device was implanted, with even higher rates in those who decided to have it removed.¹⁷

Neurostimulation devices can help women, especially since these devices target almost all levels of pain pathway including failed back surgery syndrome, complex regional pain syndrome, chronic pelvic pain, chronic facial pain and headache. All these conditions disproportionately impact women. New research on devices is currently underway to treat and manage these pain conditions, including pelvic pain, migraine and facial pain (trigeminal neuralgia). “About a third

of patients do very well,” she said. “It’s trying to figure out who those right people are to have this work on.”

KEY POINT

Neuromodulation offers a nonpharmacologic option to individuals with chronic pain, but effectiveness varies widely.

Management of Pain



Sources: Fine PG, et al. *J Support Oncol.* 2004;2(suppl 4):S5-S22.

Portenoy RK, et al. In: Lowinson JH, et al, eds. *Substance Abuse: A Comprehensive Textbook.* 4th ed. Philadelphia, PA: Lippincott, Williams & Wilkins; 2005:863-903.

FINDING YOUR VOICE

“Your pain makes you no different than anybody else. You’re the same person you have always been. You’re equal to everyone else. Pain is just a part of who you are.”

– **Penney Cowan**, founder and CEO of the American Chronic Pain Association

Application of Behavioral Strategies and Interventions for Pain Control

Michael T. Smith, PhD

Professor of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine

After a brief explanation of the science of sleep, Dr. Smith launched into his main focus: the relationship between sleep and pain. Several sleep disorders are associated with chronic pain, he said, including insomnia, sleep apnea, circadian rhythm disorders and restless leg syndrome.

The connection between sleep and pain appears bi-directional, with studies showing that pain sensitivity is amplified after sleep deprivation. In fact, longitudinal studies find that people without chronic pain who have poor sleep are more likely to have chronic pain a few years later, particularly women. And if you already have chronic pain and poor sleep, studies find a higher risk of pain spreading from a localized region to a more widespread pain.¹⁸⁻²⁰

But the opposite is also true. In one study of 679 women with fibromyalgia, those who reported good sleep were three times more likely to have their pain resolve.

All of these effects appear more prominent in women.^{18,20}

Which is why improving sleep quality could also improve—and possibly prevent—chronic pain. Effective approaches include:

Cognitive behavioral therapy, a highly focused, short-term treatment that addresses the underlying, non-physical causes of insomnia. “It’s just four sessions and it’s incredibly effective and typically recommended as first line treatment for insomnia,” he said.

It can be as effective as the best sleeping pills, has minimal side effects and is a durable treatment, he noted. However, future research is needed to successfully integrate cognitive behavioral therapy for insomnia with pain management interventions to improve pain outcomes.

Stimulus control therapy, which trains you to associate your bed and bedroom with just two things: sleep and sex. Here people are taught to go to bed only when sleepy. If they are not asleep within 15 to 20 minutes, they get up and return to bed only when they’re sleepy.

Sleep restriction therapy, in which people rebuild their sleep by taking advantage of partial sleep deprivation. A person who is only getting five hours of sleep despite 10 hours in bed would push their bedtime forward, so they go to bed just five hours before daylight. “This primes your homeostatic drive to sleep a bit more and it overcomes that hyperarousal,” he said.

KEY POINT

Sleep and pain are inextricably linked. Improving sleep may reduce pain sensitivity, while improving pain may improve sleep.

FINDING YOUR VOICE

“As a person with pain, my advice is to always follow your gut with any and all pain care and don’t give your power away to a doctor. Because when that doctor inevitably fails you, gives up on you, and says that you’re crazy, your pain is all in your head, or tells you that you have to learn to live with it, you have nowhere to go. But if we hold on to our power, we don’t give up on ourselves.”

– **Cynthia Toussaint**, diagnosed with complex regional pain syndrome after a minor ballet injury. She is co-founder of the advocacy organization For Grace.

Evidence-Based Efficacy of Noninvasive Nonpharmacological Approaches and Their Effectiveness in Treating and Managing Chronic Pain

Marie Hoeger Bement, PhD
Associate Professor, Marquette University

“It’s really important that we’re looking at the entire picture of what is pain.”

– Marie Hoeger Bement, PhD

Dr. Bement’s presentation began with a discussion of the biopsychosocial components of pain. Pain, she said, is an interaction between biological, psychological, and sociocultural factors.

- **Biological:** disease activity, physical conditioning, body composition
- **Psychological:** coping skills, helplessness, stress, anxiety, catastrophizing, fear of movement
- **Sociocultural:** social support, partner response, cultural practices

The holistic nature of pain should make non-drug management a first-line option for treating pain, with or without pharmacological options, said Dr. Bement. “Clearly, there’s room for both to optimize pain management.” She highlighted four such options, all of which should be part of a comprehensive pain management approach.

1. **Patient education.** This involves educating patients about the sensory and emotional experience of pain. For instance, the emotional side of pain may manifest as fear avoidance behaviors in exercise; catastrophizing the pain; anxiety and depression. The education should also distinguish between acute and chronic pain and the mechanisms of each. Patients need to be educated on the biopsychosocial model of pain to help them understand and better manage pain.
2. **Manual therapy.** Although manual therapy provides short-term relief, a more personalized approach includes adding exercise, joint mobilization, massage and soft-tissue mobilization, all of which can provide short-term pain relief.

3. **Electrotherapy.** Most patients with chronic pain would benefit from transcutaneous electrical nerve stimulator (TENS), she said. The TENS unit sends electrical pulses through the skin to trigger endogenous opioids and other substances within the pain modulatory system, interrupting the flow of pain signals to the brain. TENS also helps promote movement and function.
4. **Physical activity and exercise.** People who regularly participate in physical activity are less likely to develop chronic musculoskeletal pain, according to the results of a large, population-based study that followed participants over 11 years.²¹ “I think that’s huge,” Dr. Bement said. In addition, physical activity can inhibit pain even though exercise can initially increase pain. Her research and others’ have found when people are more physically active, they have less pain sensitivity coming from the spinal cord.²² Although majority of exercise training studies pain relief for people living with chronic pain, evidence shows walking to be most effective.

KEY POINT

Pain management should start with—and always include—nonpharmacologic approaches, including education, manual therapy, electrotherapy and physical activity.

FINDING YOUR VOICE

“With high-impact chronic pain, when you’re taking care of somebody, it can be very chaotic, it can be very maddening.”

– **John Garrett**, caregiver for Cynthia Touissant and co-founder of the advocacy organization For Grace

Role of a Strategist to Help Patients Improve Pain and Overcome Daily Frustrations

Lindsay Weitzel, PhD
Migraine Strategist and Medical Writer

"To emerge from pain, women have to gain exceptional control of their mental, emotional and lifestyle factors at the superhero level."

– Lindsay Weitzel, PhD

Dr. Weitzel highlighted her own role as a longtime migraine sufferer with daily migraines from age 4 to age 30, who today advocates for people with migraine.

She calls herself a migraine strategist. "I build brick walls of very personalized migraine strategy to keep people's migraine out," she said.

An important component of her approach is the "healing mindset," reassuring those she sees that the pain is not their fault. "Somewhere along the line someone has convinced them that it's their fault, that they have horrible control over their mental life, over their emotions, over whatever, and basically they just need to get it together and it's their fault they're sick."

Among her strategies:

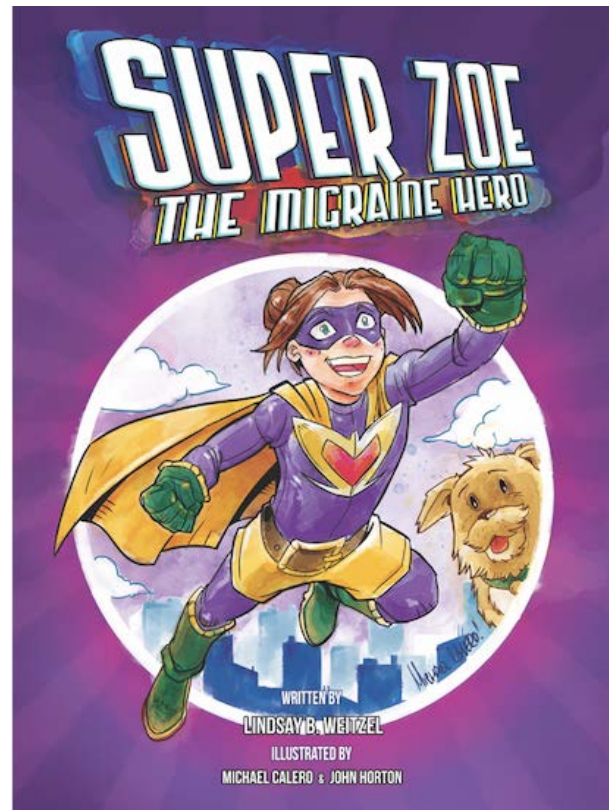
- **Empower yourself.** "Victims don't get better."
- **Refocus your idea of a pain-free life.** Rather than dwelling on the pre-pain past, focus on the post-pain future. She has her clients create a vision board of who they want to become.
- **Throw out the pain scale.** "We don't need 1 to 10. We need to know if you're thriving, functional, or homebound or bedridden. Nothing else matters."
- **Develop an exercise plan.** About half of women with migraine develop kinesophobia, defined as an irrational and debilitating fear of physical movement and activity resulting from a feeling of vulnerability due to painful injury or reinjury.

She works with her clients to identify physical activities they feel comfortable with.

- **Raise emotional frequency.** That means creating a continuum of emotions from blissful to miserable and regularly checking in to see where they are. If it's low, she helps her clients prepare a list of strategies to raise the level.

KEY POINT

Women have the power to move beyond their pain; they just have to realize and exercise it.



Created by Dr. Weitzel to empower children with migraine, Super Zoe offers supportive and positive mantras to navigate "bummer days" and other insights for children managing chronic migraine pain.

Importance of Self-Management in Chronic Pain

Yvonne D'Arcy, MS, APRN-C, CNS, FAANP
 Co-Chair of Pain Management Specialty Practice Group
 American Association of Nurse Practitioners

“Your patient has everything you need to know about their pain, and they can tell you about it, if you’ll just listen to what they’re saying to you.”

– Yvonne D'Arcy, MS, APRN-C, CNS, FAANP

Despite the critical importance of listening to patients talk about their pain, women are often left out of the process, said Ms. D'Arcy. “They feel very defeated, very unheard, and you’re going to have to encourage them to talk to you about their pain.”

She highlighted how clinicians need to interact with patients who have chronic pain and encourage greater patient participation.

- **Choose an achievable goal that reflects the patient’s preferences and abilities.** “If you choose something the patient can’t achieve, they feel very defeated.” That includes educating them that their pain may never disappear entirely, but they will be better able to manage it.
- **Offer options that appeal to the patient.** “You don’t just hand them a sheet of exercises and say, ‘Now go home and try some of these,’ because you’re going to be really doomed to failure,” she said.
- **Support the patient.** That means ensuring them that you will be with them (although also setting boundaries) and continue to try new approaches. It also means offering tools so patients can see success, like pain diaries to track not just the level of pain, but functionality.

One way to improve patient self-care is through motivational interviewing, she said, which helps patients identify barriers to success and encourages their involvement in the treatment plan.

“The thing that’s going to help anybody the most is to listen to what the patient is telling you about their pain, how it is affecting their lives, how their treatments are working, and how you can actually better develop the plan,” she said.

THE FOUR BASIC SKILLS OF MOTIVATIONAL INTERVIEWING

- **Open:** Asking open-ended questions
- **Affirming:** Accentuating the positive
- **Reflecting:** Practicing reflective listening
- **Summarizing:** Summarizing concepts and reflecting back

KEY POINT

Clinicians need to view pain more from the patient perspective and implement approaches that meet the patient’s goals.

“ FINDING YOUR VOICE

“When you get involved in advocacy or when you find your voice, what you are doing is actually taking back some control from a life where you have lost a lot of control. That is empowering. It transforms you. Even a little voice creates a little ripple, that causes other ripples, and eventually all those ripples become a wave. You can be one of those little ripples that makes a difference.”

– **Shoshana Lipson**, founder of the CGRP and Migraine Community, and the blog, *migrainemeanderings*

SESSION 3. BARRIERS AND CHALLENGES IN PAIN TREATMENT AND MANAGEMENT

Barriers to Providing Integrative Pain Care

Bob Twillman, PhD

Clinical Associate Professor of Psychiatry, University of Kansas Medical Center

“We’re going to spend the next decade with everybody telling us we should be using complementary and alternative treatments and nobody being willing to pay for it.”

– Bob Twillman, PhD

About a third of Americans use some sort of complementary or integrative health treatment, with women 50 percent more likely to use them than men. And many of these approaches are effective for common chronic pain conditions, Dr. Twillman said.

While current guidelines call for using integrative treatments for pain, “actually getting those treatments is a bigger challenge than perhaps many people realize.”

For instance, in 2018, the Agency for Health Research and Quality released a report on nonpharmacologic, noninvasive treatments for pain that found good evidence of the effectiveness of acupuncture in treating low back pain, neck pain and fibromyalgia.²³ Several other reviews find similar results, and some health care organizations, including the Centers for Disease Control and Prevention, also recommend acupuncture for various chronic pain conditions.^{24,25}

However, patient access is limited, primarily because of lack of insurance coverage and reimbursement issues. Other barriers include lack of education among medical professionals; few integrative pain care providers; lack of referral networks; and missing quality indicators.

“The ultimate effect is that many people with pain who want to use these treatments are effectively prevented from using them for any one or more of these reasons,” he said.

OPPORTUNITIES TO IMPROVE ACCESS TO INTEGRATIVE CARE

- Provide better training and education in medical and nursing schools.
- Encourage continuing medical education programs.
- Create directories of providers.
- Increase the professional training pipelines for integrative medicine practitioners.
- Start a data registry to improve evidence collection.

Although insurance companies say they don’t cover nonpharmacologic treatments because of a lack of high-quality and long-term evidence of effectiveness, “this seems perhaps a little bit hypocritical,” he said. “Insurance companies cover long-term opioid therapy (for chronic pain), despite the fact that the evidence is no better.”

It is particularly challenging to get coverage under Medicare, he said, which requires that nonpharmacologic therapies provide evidence the treatment is efficacious and safe in the 65 and older population. “That’s a challenge because Medicare populations frequently are excluded from clinical trials, and if they’re included, they’re a small minority of the trial, and you can’t pull their data out because you lose too much statistical power to make it a reasonable analysis.”

“So, we’re stuck. If we start now to develop the kind of evidence that we need to meet this standard, we’re going to be at it for a decade.”

KEY POINT

Integrative medicine is very effective for pain management, yet numerous barriers prevent its widespread use, particularly lack of insurance coverage.

Challenges to Pain Treatment Unique to Women

Mary Driscoll, PhD

Clinical Research Psychologist, Yale School of Medicine; PRIME Center, VA Connecticut Healthcare System, VA Women’s Health Services

“It’s amazing women get care at all.”

– Mary Driscoll, PhD

Dr. Driscoll highlighted not only the specific barriers to pain management women face, but possible solutions. Understanding the barriers, she said, requires applying the biopsychosocial model of pain to women:

- Women have unique biological barriers and challenges, including pain conditions of unknown etiology, often suffering for years without a diagnosis, which affects management and treatment.
- Women are more likely to have pain conditions with a hormonal element, such as menstrual migraines, while reproductive hormones may make managing pain challenging at different times in life.
- Women appear to respond differentially to opioids and even nonpharmacological approaches.
- Women are more likely to experience comorbid depression with pain.
- Women with pain have high rates of interpersonal trauma, with post-traumatic stress syndrome associated with higher pain intensity, greater disability and greater emotional distress.
- Women are often subject to stigma from friends, family and the medical establishment, routinely hearing that “the pain is in your head.”
- Women are less likely to be queried about pain at medical appointments.
- The overemphasis on the biological cause of pain often results in undertreatment and in a discounting of women’s experience.
- Women communicate differently about their pain, becoming more emotional in their reporting, thereby leading to a discounting of the severity and impacting care.
- Women report more guilt/fear about how pain may affect others, and they struggle to set limits with others to allow time for self-care (relational issues).

“Taken together, these factors paint a challenging picture for women when it comes to the treatment and management of pain,” said Dr. Driscoll.

To overcome these barriers, providers must:

- **Validate and address the burden of pain with empathy.** “Until a woman feels heard and understood, you’re not getting anywhere.”

- **Improve communication.** Be transparent about treatment decisions especially when expectations are at odds with treatment guidelines.
- **Practice trauma-informed care.** Assume every person with pain may have a history of prior trauma that affects their interactions with the health care system and act accordingly.
- **Sensitively address mental health.** Trauma and depression can’t be left out of the treatment plan, but it needs to be addressed sensitively.

Women also need to help providers engage in these conversations, she said. They need to reflect on the impact the pain has on their life barriers to managing their pain; and their vision of how things should be different in six months. “And then communicate these to your provider and ask for strategies that can help address what’s most distressing.”

KEY POINT The unique challenges that women face when dealing with chronic pain mean that providers need to embrace a new paradigm of communication.

WOMEN VETERANS AND CHRONIC PAIN

Dr. Driscoll also highlighted her work with women veterans, whom she calls “the most resilient group of women I’ve ever met in my entire life.”

Although there are two million female veterans in this country, just one-fifth receive care from the Veterans Administration (VA). Yet 70 percent of women veterans report chronic pain. They have a unique risk for pain given the physicality of their jobs, she said, which leads to high rates of injury. And women don’t like to present for care while on active duty because they don’t want to call attention to themselves. Finally, she said, women veterans experience a lot of trauma, both combat and military sexual trauma.

They also have multi-occurring pain conditions, are juggling multiple roles and demands, are often stigmatized and isolated with little social support, and have a difficult time coordinating care between the VA and civilian providers.

“So, when you are working with women, whether you know they were a service member or not, ask them, ‘Did you serve?’ If they did, assess for exposures, connection to VA services, eligibility for VA services, and many of the other barriers.”

Challenges Pregnant Women Face With Opioids— Gender Differences in Pain and Substance Use Disorders

Shruti Kulkarni, JD

Attorney, DCBA Law & Policy and Board of Directors, Female Opioid Research and Clinical Experts

While all women face significant challenges in obtaining pain medication, the situation is particularly difficult for pregnant women who require opioids, Ms. Kulkarni said. Twenty-three states and the District of Columbia allow substance use during pregnancy to be classified as child abuse, and 24 states and Washington, DC, require practitioners to report suspected prenatal drug use.

Pregnant and parenting women also tend to have far fewer options for treatment. Only 19 states have programs designed for pregnant woman, only 15 percent of treatment centers nationally offer specific services for pregnant or parenting women and just 10 states prohibit publicly funded drug treatment programs from discriminating against pregnant women.

She highlighted efforts at the federal level to address these issues, including:

- **Diverse Women in Clinical Trial Initiative.** This joint initiative between the Food and Drug Administration and the National Institutes of Health (NIH) Office on Research in Women's Health is designed to raise awareness about the importance of including diverse groups of women in clinical research, and to share best practices about clinical research design, recruitment, and subpopulation analyses.
- **Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC).** The 21st Century Cures Act established the PRGLAC Task Force, led by NIH, to advise the Secretary of Health and Human Services regarding gaps in knowledge and research on safe and effective therapies for pregnant women and lactating women.

KEY POINT

There are numerous challenges to finding treatment for addiction in pregnant women and those with children.

Unique Barriers to Women Seeking Treatment

GREATER RISK OF ARREST AND CRIMINALIZATION

- Twenty-three states and the District of Columbia consider substance use during pregnancy to be child abuse; three consider it grounds for civil commitment.
- Twenty-four states and the District of Columbia require health care professionals to report suspected prenatal drug use.

LACK OF ACCESS

- Only 19 states have treatment programs specifically designed for pregnant women.
- Ten states prohibit publicly funded drug treatment programs from discriminating against pregnant women.

LACK OF CHILDCARE

Pain Management Best Practices Inter-Agency Task Force Report



“Central to the unique issues women face in pain management are the differences between men and women with respect to pain sensitivity, response to pain medication, and predisposition to clinical pain conditions.”

There also is a need for participation by Ob/Gyns in pain management for women during pregnancy and postpartum stages.

RECOMMENDATIONS:

- Conduct more research on sex differences in pain responses and therapies
- Increase awareness of unique challenges with regards to pain for women during pregnancy and postpartum
- Include Ob/Gyns in multidisciplinary care teams

FINDING YOUR VOICE

“I cannot ever remember a time when I did not have debilitating migraine.”

– **Shoshana Lipson**, founder of the CGRP and Migraine Community, and the blog, [migrainemeanderings](http://migrainemeanderings.com)

Overcoming Health Care Challenges: Maneuvering Through Communication, Access and Cost Barriers While Dealing With Chronic Pain

Jamie M. Sanders

Migraine Advocacy Patient Coordinator, GHLF/50-State Network, and patient advocate/blogger, The Migraine Diva

“It is incredibly challenging to manage a chronic disease and an uncompromising health care system at the same time.”

– Jamie M. Sanders

“There are several barriers that people like me must overcome in order to be moderately successful in navigating the health care system,” said longtime migraine sufferer and advocate Ms. Sanders. “Help is not always available or known to patients when needed, and the burden is often placed on the patient to find solutions.”

Other barriers include language, culture, race and gender; short physician visits; the stigma women in pain face; cost; access to specialists; and access to medical devices.

Communication between health care providers and women is key to overcoming existing prejudices, which can lead to symptoms being misdiagnosed as stress, inability to cope, lack of healthy lifestyle or as a character or personality trait. (Figure 4.)

Cost and access to health care and medical specialists are huge barriers for women to overcome. Insurance companies create their own barriers through step therapy and preauthorizations for certain medications like the calcitonin gene-related peptide inhibitors.

“These policies harm patients because they create additional barriers that can lead to people foregoing their medications,” Ms. Sanders said. “This can also make the medical condition worse, increasing the need for medical intervention and the cost of health care.”

IMPROVING HEALTH CARE ACCESS FOR PATIENTS WITH CHRONIC MIGRAINE

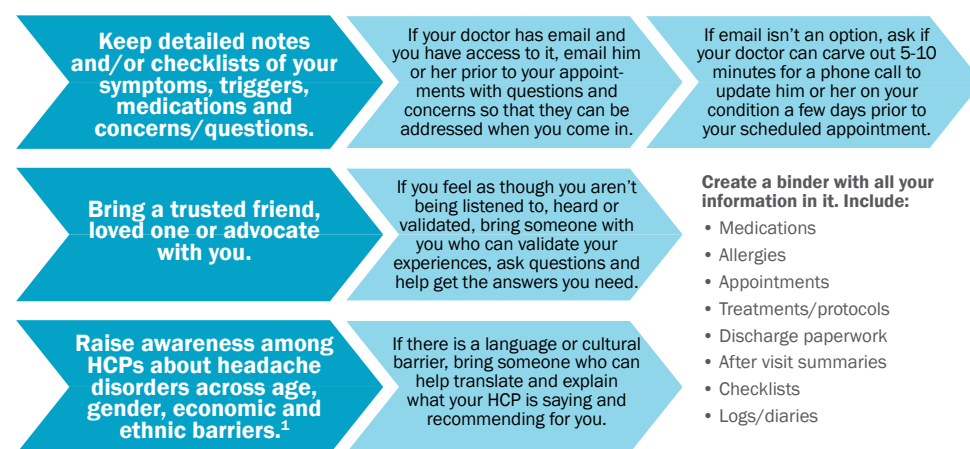
Ms. Sanders suggests the following to improve health care access for women with migraine:

1. Provide patients with clear and easy to understand information about insurance policies, terms and appeal processes.
2. Provide more education to patients about the use of noninvasive nondrug treatments and complementary and alternative medicine.
3. Eliminate pharmacy benefit policies that override doctors’ decisions.
4. Provide medical education about migraine and headache disorders to all health care providers.
5. Openly address the stigma surrounding migraine and raise awareness about the seriousness of migraine disease.

KEY POINT

The health care system itself presents an often-impassable barrier to women seeking help for their chronic pain.

Figure 4: Ways to Improve Communication



1. Migraine Therapies in Women. www.healthywomen.org/content/article/science-technology-and-innovation-roundtable-migraine-therapies-women.



OFFICE OF WOMEN'S HEALTH, FDA
OFFICE OF RESEARCH ON WOMEN'S HEALTH, NIH

Updates from the Federal Offices of Women's Health

The final session of the first day involved two representatives from federal offices of women's health: Kaveeta Vasisht, MD, PharmD, acting associate commissioner of the Office of Women's Health at the Food and Drug Administration (FDA), and David Thomas, PhD, special advisor to the director, Office of Research on Women's Health at the National Institutes of Health (NIH).

Dr. Vasisht's office functions as an advisor to the FDA commissioner on political, ethical and scientific issues pertaining to women's health; works to promote the inclusion of women in clinical trials; addresses cost-cutting initiatives and emerging issues; and serves as the agency's liaison on women's health externally and internally.

"Our office tries to look across the drug development enterprise and the FDA's regulatory purview through a sex- and gender-specific lens."

In 2018, her office held a two-day conference examining the influences of sex and gender on opioid and nicotine use, dependence and recovery. The key takeaways on the salient influences of substance use in women include:

- Stress
- Pain
- Relief of negative affect
- Social factors
- Adverse early life events
- Escalation of opioid misuse, which is faster in women than men, a phenomenon known as telescoping
- Greater relationship influence on nicotine and opioid addiction in women than in men
- Addiction neurobiology involves multiple sexually dimorphic circuits, cell types and neurotransmitter systems
- Overlap of the brain's reward circuits that control pain and stress, leading women to experience and crave drugs differently than men

- Hormone modulation of pain, reward, craving and withdrawal
- Neurobiological sex differences that underlie male-female differences in addiction onset, experience and recovery
- Significantly lower levels of analgesia produced by opioids in females
- Underutilized medication-assisted treatment
- Data gaps in knowledge of sex and gender on substance use and misuse

The NIH office is designed to advance rigorous research that is relevant to the health of women; develop methods and leverage data sources to consider sex and gender influences that enhance research for the health of women; and help disseminate and implement scientific evidence to improve the health of women.

Dr. Thomas highlighted the Helping to End Addiction Long-term (HEAL) Initiative, a trans-agency effort to advance scientific solutions to the double crisis of pain and opioid addiction.

What sets this initiative apart from others is that it focuses on communities to address the opioid epidemic, rather than on individuals. It is also developing a research network for pain and greater support for research to identify nonaddictive pain treatments.

One key area of focus is identifying objective measures of pain from the patient perspective and better understanding—and perhaps preventing—the transition from acute to chronic pain.

"We have a tremendous opportunity to help people if we do it right," said Dr. Thomas.

KEY POINT

Federal agencies are aware of and involved in the significant issues related to chronic pain in the U.S.

KEYNOTE PRESENTATION

Bias Against Women in the Treatment of Pain

Diane E. Hoffmann, JD

Professor of Health Care Law, University of Maryland

Ms. Hoffmann's entry into the world of chronic pain began with an article she published in 2001, "The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain."²⁶ Researching the issue of pain from its legal implications, she was surprised to learn about numerous disparities in pain management between women and men, including the fact that women were less likely to receive pain medication when they complained about pain and more likely to receive sedatives.

"This really distressed and angered me," she said. "Why is this? Is there a biological basis for men and women being treated differently? Do they report pain differently? And if there is a difference in treatment, is that justified by the first two findings?"

Legal and ethical principles of justice say that similarly situated people should be treated similarly, she said, and differently situated people should be treated differently. "It's not that we necessarily want to treat everyone the same," she said, "but we want to treat everyone in the amount they need to reach the same outcome."

Her article triggered a broader discussion of the topic of pain in women, including a story in the *New York Times* in 2003 that confirmed her findings via interviews with pain specialists throughout the country.

"But what continues to surprise me," she said, "is that I still get calls from reporters and journalists and people cite this article, even though it's now almost 20 years old." So, she returned to the literature, finding that although there has been progress in understanding biological differences related to pain in men and women, well-designed clinical trials on disparate treatment differences were still rare and numerous disparities and challenges for women with acute and chronic pain still exist. For instance:

- Forty percent of women with chronic vulvar pain remain undiagnosed even after three medical consultations.²⁷
 - Half of women with endometriosis see at least five health care professionals before receiving a diagnosis or referral.²⁸
 - Gender plays a significant role in whether a patient presenting to the emergency department with injuries or abdominal pain receives appropriate analgesia and how quickly they receive it.^{29,30} In both instances, women were less likely than men to receive pain medication.
- "Why are there still such differences?" she asked.
- She cited several possible factors:
- Physician implicit bias or underlying attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner.
 - The lack of women and even female animals in basic and clinical research on pain.
 - Lack of physician education.
 - Overlapping pain-related conditions in women.
 - Physician uncertainty regarding a diagnosis, which may lead them to normalize a woman's symptoms instead of trying to diagnose the underlying condition.
 - Communication between women and their doctors. For instance, she said, women are more likely to use words and graphic language than men and typically focus on the sensory aspect of the pain. Men use fewer words, less descriptive language and focus on events and emotions. Men's pain is often attributed to something very specific while women's may be attributed to stress or fatigue.
- "My perspective is that education is really going to be the most effective thing" to resolve disparities, she said.

KEY POINT

Health care providers require extensive education about pain in women and how to diagnose and treat it, as well as how to communicate with their pain patients.

Racial and Ethnic Disparities, Lived Pain Experiences and Stigma

Carmen Green, MD

Professor, Anesthesiology, Obstetrics and Gynecology, and Health Management and Policy, University of Michigan



“The unequal burden and the unheard voices of women, particularly women of color, are, I believe, one of the most pressing needs in pain research.”

– Carmen Green, MD

By 2024, the majority of Americans will be non-white. Yet, the whole conversation of disparities related to pain, particularly in women of color, has not been handled well, according to Dr. Green.

“We need to think about how to provide better care and do better science in order to prove pain in various populations.” For instance, she said, while gender may be a biologic variable in pain, how does diversity play into that finding?

We need to know more because the world is changing, Dr. Green emphasized. “It’s like pantyhose: One size doesn’t fit all.”

One area that should be studied more critically, Dr. Green said, is the social determinants of health.

For instance, when she and colleagues conducted a study looking at the availability of opioids by zip code in Detroit, they found that while pharmacies in primarily white neighborhoods carried a sufficient supply of opioids, even in low-income communities, those in minority neighborhoods, even in higher-income neighborhoods, had sufficient supply only half the time.³¹ “So race is protective if you are white, but money is not protective, if you are a person of color,” she said.

Too often, she said, people of color and those who are impoverished in the U.S. die earlier. It’s time, she said, to conduct the research needed to change this pattern.

While the data is clear about poor assessments, lack of access and poorer outcomes as it relates to women, when this data is extrapolated for minorities, it’s lacking, according to Dr. Green. “We need that data, and it begins by having some difficult conversations and communication about our history.”

KEY POINT

There are numerous disparities in pain management, not just sex- and gender-based, but race, ethnicity and age, among others.



“It is more important to know what kind of person has a disease than the disease.”

–Sir William Osler

Dr. Green suggested we need to start having those hard conversations and thinking about these issues, critically:

- How do we improve the quality of care?
- How do we improve the communication between the clinician and the patient?
- How do we teach patients to do some of the things they need to do, like self-management?
- How do we teach physicians how to make certain they give patients good care?
- How do we acknowledge our personal biases and get past them so we can improve patient outcomes?

“The science needs to come along, and we need to keep asking ‘How do we provide good quality care for all populations?’ There is no reason for people to have to suffer because of what they look like,” said Dr. Green.

“Of all the injustices, injustice in health is the most shocking and most inhumane.”

– Martin Luther King

Implementing the National Pain Strategy at the State Level to Improve Education About and Treatment of Chronic Pain

Cynthia Toussaint
Co-founder, For Grace

Ms. Toussaint focused on the work of her organization, For Grace, to implement a statewide pain strategy in California. The mission of For Grace is to raise awareness of complex regional pain syndrome (CRPS) and also promote care and wellness of women in pain. The effort began with a summit in 2017 to educate individuals living with pain and their caregivers about the National Pain Strategy, a multiagency effort to reduce the burden of chronic pain, then continued with a summit of professionals the following year. The result was a commitment to develop a California-specific pain strategy to address the unique challenges that people with pain face.

“We are going to strongly urge the California legislature to implement a pain center under the state’s Health and Human Services Department to promote centers of excellence, better pain management education, better insurance coverage of comprehensive pain care and public education about pain,” she explained.

“The National Pain Strategy is an excellent blueprint for optimal pain care,” she said, encouraging participants to use it to develop a plan for their own states.

KEY POINT

Pain advocates should develop their own roadmaps at the state level to improve the delivery of pain-related care.

Road to Sacramento

This legislative/policy recommendation serves as a statewide pain strategy. It includes the goal to create a pain center administered under the state’s Health and Human Services agency. The Pain Center would implement the following:

1. Establish a network of Comprehensive Integrative Pain Treatment and Research Centers of Excellence across the state.
2. Improve and expand pain management education/training opportunities for all types of health care providers (and students).
3. Work with state agencies responsible for state employee health insurance, Medi-Cal coverage and workers’ Compensation to revise coverage and reimbursement policies for chronic pain.
4. Develop and implement statewide public health campaign to educate California residents about chronic pain and chronic pain patients about pain treatment options including self-care.



FINDING YOUR VOICE

“There is only one difference between caregivers and people living with pain, and that is the caregiver doesn’t feel the physical pain, but they experience absolutely everything else experienced by a person with pain—the frustration, the guilt, the anger, the confusion—all of it.

– **Penney Cowan**, founder and CEO of the American Chronic Pain Association



Opioid Addiction in Women: Short- and Long-Term Implications

Kim Templeton, MD

Member, Board of Directors, American Medical Women's Association

Dr. Templeton highlighted several issues related to sex-based differences throughout her presentation on the short- and long-term use of opioids:

- Women tend to be given opioids at higher doses over longer periods of time than men.
- Women are prescribed opioids in combination with benzodiazepines. Both are respiratory depressants and thus contraindicated in combination.³²
- Studies in animal models demonstrate that mu opioid receptor density and binding affinity may be affected by estrogen levels among females.³³ Male animal models demonstrate longer-lasting pain relief from opioids than do females, which reflects in part the influence of testosterone.³⁴ The influence of sex hormones on mu opioid receptors may also help to explain why women are more likely than men to overdose as a result of respiratory depression.³⁵
- Additional research is needed to better understand the fluctuations of sex hormones in the setting of chronic pain and the impact of these hormones on mu opioid receptors, pain relief and risk of respiratory depression.



FINDING YOUR VOICE

“I think it’s absolutely OK to take care of yourself. Again, this is a marathon, it’s not a sprint, and you’re doing one of the greatest things human beings can do—You’re taking care of someone you love.

– **John Garrett**, caregiver for Cynthia Touissant and co-founder of the advocacy organization For Grace



A key area to consider when discussing chronic pain in women is underlying mental health issues, she said, including depression, anxiety and post-traumatic stress disorder (PTSD), which may alter pain perception.³⁶

For instance, she said, “We know that opioid use disorder (OUD) is more common among women who have a history of intimate partner violence, but why is that? Is it, to some degree, self-medication?”³⁷

She also addressed the issue of multiple provider episodes (MPEs), in which patients see several health care professionals for prescriptions and/or go to several pharmacies to get them filled. In Kansas, she said, women account for about two-thirds of people with MPEs. Possible reasons include:

- Their pain isn’t taken seriously, so they have to seek help elsewhere.
- Their provider “fires” them because their pain doesn’t improve.
- They are undertreated.
- They respond differently than men to opioids.
- Providers don’t understand the underlying issues that may contribute to a woman’s pain.

She also noted differences in the rate of OUD between men and women. While men are more likely to exhibit OUD when younger, women are more likely to report it after age 68.³⁸ Women with OUD are also more likely than men to report psychologic distress and to be using cocaine and marijuana.³⁹ Yet, fewer women enter treatment for OUD, she said, in part because of stigma. Women also tend to have higher rates of relapse than men.⁴⁰

“Is this because biologically the addiction is different?” she asked, “Or is it because women leave treatment earlier because of caregiver issues?” As with every other health condition, “Women tend to prioritize everybody before their own health,” she noted.

Another issue, she said, is that treatment is based around a male model that doesn't account for pregnancy or child-care needs. Yet, about a third of pregnant women undergoing addiction treatment have OUD. "This is a huge issue," she said. "How do we get women through treatment, so they understand the long-term implications of addiction? How do we address opioid use among women of childbearing age earlier, so that women are not risking having a child with neonatal opioid withdrawal syndrome?"

She concluded by noting the need for more research in order to better understand sex and gender differences in pain, particularly in response to opioids, and the interplay between mental health conditions and pain.

KEY POINT

There is a need for women-focused addiction treatment programs that address the unique needs of women.

NOVEL PERSONALIZED SOLUTIONS FOR PREVENTING OPIOID USE DISORDER

Take a 59-year-old woman with fibromyalgia, a history of a previous opioid overdose, chronic respiratory disease, anxiety and depression. Add to that a prescription for opioids and benzodiazepines and what do you get? Multiple hospital and emergency department visits and, despite this, continuing prescriptions for opioids.

This isn't a "what if" case, but an actual patient, said Elizabeth Ann Stringer, PhD, chief science and clinical officer for axialHealthcare, during her talk on breakthrough solutions for pain and opioid care.

"This happens all too often," she said.

That's where her company comes in. Axial uses proprietary analytics to mine insurance claims and other patient data to assess the patient's medical condition, demographics and treatment plan. "Then we can build out these histories for every patient and begin to understand if the patient is receiving optimal care and where care can be improved," she explained. This can also help predict who is at risk for OUD.

The information is shared with the patient's physician as an opioid risk report. It highlights the patient's high-risk attributes and the treatments that may contribute to this increased risk. "But it's not enough just to analyze and highlight an individual's risk," Dr. Stringer said. "We want to take actionable next steps to decrease the risk for poor outcomes." Thus, a care team of pharmacists and health coaches works with the provider to develop care plans to improve outcomes.

The Patient Voice in Pain and Development of Pain Therapeutics

Peter Pitts

President, Center for Medicine in the Public Interest

“How are we going to bring novel pain management approaches to market without serious, thoughtful, scientific input from patients?”

– Peter Pitts, President, Center for Medicine in the Public Interest

Although the Food and Drug Administration (FDA) has approved 13 new analgesics in the past five years, 11 were variants of opioids and two were variants of existing molecules. None were new chemical entities. Thus, Peter Pitts, president of the Center for Medicine in the Public Interest, gave the agency a “D” grade on new drug development during his talk, *The Patient Voice in Pain and Development of Pain Therapeutics*.

“Unless we insert a new variable, new entities are not going to happen,” said Pitts. “That new variable is the voice of the patient. However, he said, “The patient voice has to evolve from tellers of sad stories to partners in science in order to be seriously considered in drug development and drug review conversations.” It has to be, he said, “the voice of the patient who understands regulatory science and drug development.”

This is a major challenge, he admitted, particularly since scientists and patients address disease topics from different perspectives. “It’s hard to talk to a scientist about quality-of-life measurements because they’ve been taught their entire career that it’s meaningless data, and it’s tough to talk to patients about randomized controlled clinical trials and *P* values because they don’t know what you’re talking about.”

That is changing under the FDA’s patient-focused drug development program, which requires that drug

sponsors involve patients in clinical trial design and that regulators consider patient concerns when evaluating drugs for approval.

For instance, patient advocates for Duchenne’s muscular dystrophy actually drafted the regulatory guidance for drug development for the disease. “Think about that,” Pitts said. “Patient groups working with the FDA to write the guidance as to how drugs for their disease state should be addressed. That’s partnership.”

However, few patient organizations have the expertise to take that on. “Who is training the patient groups to evolve into scientific partners of data?” he asked.

KEY POINT

Patient advocates need to better understand the science around pain and clinical trials, while researchers need to better understand the unique needs of people dealing with chronic pain.

FINDING YOUR VOICE

“You’ve got to find your people and let them lift you up and hold you down when you need it, because they will help you tap into that core, authentic inner voice.”

– Jenni Grover, founder of ChronicBabe

SESSION 5:

Bring About Change Through Policy

Three speakers addressed the role of the federal government and its policies in pain management and research.

Cindy Steinberg

National Director, Policy and Advocacy, U.S. Pain Foundation

“Pain policy is really a complicated puzzle with many different authorities and jurisdictions owning control of different parts of the puzzle.”

– Cindy Steinberg, National Director of Policy and Advocacy, U.S. Pain Foundation

Ms. Steinberg focused on the lack of coordination among public entities when it comes to pain. For instance, state medical boards control certain practice policies, but federal law determines medication scheduling and policies. Numerous agencies are involved in pain policies, including the Food and Drug Administration, Health and Human Services, the Centers for Disease Control and Prevention, the Drug Enforcement Agency, the National Institutes of Health (NIH) and various state agencies, including public health departments and Medicaid programs.

She highlighted the NIH’s HEAL initiative, a nearly \$1 billion research program designed to advance our understanding of pain by identifying biomarkers, endpoints and signatures of pain conditions, as well as providing evidence-based, nonaddictive treatments for discrete pain conditions. Part of that initiative is the Acute-to-Chronic Pain Signatures project, which seeks to understand the biological characteristics of people who are susceptible to transitioning from acute to chronic pain.

“Being successful in changing policy requires figuring out the locus of control for the issue that you’re working on and making connections, educating, convincing, cajoling, influencing, whatever you need to, to make the change,” she said.

Alicia Richmond Scott, MSW

Designated Federal Officer, Pain Management Best Practices Inter-Agency Task Force, Office of the Assistant Secretary for Health, U.S. Department of Health & Human Services

Ms. Scott discussed the recently released report from the Pain Management Best Practices Inter-Agency Task Force, noting that the task force received more than 10,000 public comments on the draft report, a sign of the interest in this topic.

“The report underscores the importance of individualized, multimodal, multidisciplinary care,” she said. “The next steps are to address research, access to care and payment issues.”

However, she stressed, “this is not the sole responsibility of the federal government. We want to make sure that there is a collaboration between the federal government and external stakeholders, including those at the state and local level governments, so we’re all on the same page and are better able to support individuals in pain.”

Ellen Blackwell, MSW

Senior Advisor, Center for Clinical Standards and Quality, Centers for Medicare & Medicaid Services (CMS)

Ms. Blackwell highlighted the numerous opportunities for consumers and clinicians to interact with the Centers for Medicare & Medicaid Services, and the agencies efforts in the area of pain management.

They include email and press release lists; serving on CMS technical expert panels; involvement with Medicaid agencies to track requested changes in coverage; providing input through CMS’s open-door forums; commenting on legislative changes published in the Federal Register; and addressing internal affairs groups.

“You can affect change by talking to your state Medicaid agency and going in and meeting with those people,” she said. “Just like us, they do want to hear from their constituents, the people that they serve.”

“I urge you to raise your voice,” she concluded. “You can’t talk to us enough.”

MEDICARE RESOURCES OF INTEREST

1-800-MEDICARE

[Chronic Conditions Warehouse](#)

[Mapping Medicare Disparities](#)

Challenges and Opportunities for the Chronic Pain Community

On Day 2, Summit participants split into four groups to hold in-depth discussions about critical issues highlighted during the meeting: access and affordability; education; patient engagement; and stigma. Some of the challenges and opportunities identified are reflected here.

ACCESS AND AFFORDABILITY

CHALLENGES

- Multimodal therapies often are not covered by insurance, limiting access to complementary therapies.
- Access to chronic pain treatment, including pain specialists, often is limited by geographic location.
- Prior authorization and practice management inexperience are common barriers.
- Lack of evidence-based data for integrative and alternative therapies prevents insurers from including them.
- The Family and Medical Leave Act is now well understood by employers and employees.

OPPORTUNITIES

- Identify best practices for treating and managing chronic pain and complex overlapping conditions.
- The next frontier in medicine will be identifying best practice for treating and managing chronic pain and complex overlapping conditions.
- Improve definitions for what quality care looks like for individuals with chronic pain, which will improve all aspects of the health care system they encounter.
- Advocate for more funding and research, as well as for more pain specialists, to help call attention to the many needs of individuals with chronic pain conditions.

EDUCATION

CHALLENGES

- More recognition is needed for the complexity, pervasiveness and range of issues associated with chronic pain conditions.
- Chronic pain is a multidisciplinary disease that requires a multidisciplinary approach.
- Payers are not engaged in discussions and solutions focused on chronic pain treatment and management coverages.
- Isolation and lack of resources contribute to poor outcomes.
- Lack of education about chronic pain contributes to stigma among health care providers, the public and patients.

OPPORTUNITIES

- Advocate for multidisciplinary treatment for chronic pain.
- Engage payers in discussions about solutions for best practice management/coverage of chronic pain conditions.
- Bring chronic pain education to Ob/Gyn and primary care settings. They must be part of the conversation.
- Improve access to resources by using technology, social media and other platforms.
- Help patients and providers understand the science behind pain, known as therapeutic neuroscience.



PATIENT ENGAGEMENT

CHALLENGES

- Patients lack awareness about their rights.
- New regulatory barriers—pharmacies checking with physicians about medications—create dehumanizing obstacles and prevent timely access to treatment.
- Too few pain specialists and delayed referrals to specialists lead to delayed diagnoses.
- Lack of diagnostics and common terminology for patients to describe symptoms undermines communication with health care teams.
- Limited time with clinicians affects need to discuss/evaluate comorbidities.

OPPORTUNITIES

- Educating patients about their rights, state laws and the process for protesting rights violations, can make them stronger advocates to help educate clinicians and lawmakers, and other chronic pain patients.
- Improved communication between clinicians and pharmacies.
- A role exists for payers and case managers to help remove barriers by engaging in the process.
- Advocacy can contribute to the evolving science exploring the dimensions of chronic pain.
- Talking about the stigma applied to chronic pain can diminish stigma's impact.

STIGMA

CHALLENGES

- Self-stigmatizing thoughts and behaviors worsen living with chronic pain.
- Pain often is an invisible condition; health care providers talk more “at than with.”
- If you tell someone you suffer from chronic pain, they assume you're an addict.
- Stigma leads to isolation, especially for women in disadvantaged environments.
- Many health care providers have biases connected with chronic pain-related conditions.

OPPORTUNITIES

- Use accommodations available and own being disabled.
- Language used to discuss chronic pain is important. Advocate against dehumanizing terms, like “addict.”
- Humanize the chronic pain story by engaging individuals living with chronic pain.
- Continue to educate health care providers about chronic pain, from the perspective of the individual with chronic pain.
- Build a team who will help you advocate with health care providers and fight stigma wherever you find it.

“If you want to be an advocate for the community, you're going to face moments day-to-day, week-to-week, where you have a moment, you have a chance to speak up.”

– Jenni Grover, founder and author, ChronicBabe

Pain, Resilience and How We Heal

Kate Nicholson

Civil rights attorney, speaker and writer

“Pain is a dance. And as any dancer knows, it's about finding a balance between strength and flexibility or strength and fragility; between surrender and fight; between learning self-care, but also letting other people take care of you; between meeting your goals and going out toward them, but also resting when you need to; between experiencing difficult emotions, truly grieving them, but then letting them go and not holding on to them.”

– Kate Nicholson, Civil rights attorney, speaker and writer

Ms. Nicholson’s chronic pain journey began more than 25 years ago with a surgical injury. “After that, I was unable to sit or stand or walk, with the exception of a couple of feet

with a walker, for the next 15 years,” she said. What she found, though, was a way to remain resilient throughout the ensuing nightmare.

She described resilience as a scale with the individual as the fulcrum and positive or negative experiences tilting the person one way or another. “Where the fulcrum sits is a little bit dependent on your genes and how you respond to negative stress. But the quality of stressors also matters, in particular the intensity and duration of the stress, which poses a problem for chronic or intractable pain.” It can overwhelm the system, she said, transforming adversity into trauma.

However, there are ways people can build resilience despite of the negative experience. The most important way is to cultivate social and cultural support, which can provide emotional scaffolding to buffer the effect of negative events. (Figure 5.)

Other techniques that have helped her over the years include meditation and relaxation therapies, journaling, drawing and taking in the works of established artists. “Art helps me experience or have a venue for the turbulence within,” she said. “I found that sketching, for example, created a calm, centered place inside me. Sketching must have used a different form of concentration because I had the energy for it.” (Figures 6).

Figure 5: ‘Art Rx’ for Chronic Pain Patients

Viewing works of art can have an analgesic effect on chronic pain and alleviate feelings of isolation for patients who suffer from it, according to a study by researchers at University of California, Davis, published in the journal *Pain Medicine*.

British Doctors May Soon Prescribe Art, Music, Dance, Singing Lessons

Campaign is expected to launch across the entire U.K. by 2023



IN BRIEF

Doctors in Quebec Will Soon Prescribe Museum Visits as Medicine

The pilot program employs art to relieve a variety of physical and mental illnesses.

Jasmine Weber October 19, 2018

16k Shares



POPULAR

- 1 This Year's UNESCO Session Was a Insult to World Heritage
- 2 Interpreting the Beasts of the Midd Ages
- 3 A Chronicle of 100 Contemporary Artists Who Use Textiles
- 4 Melania Trump Gets Her First Monument, And It's Not What You' Expect
- 5 The False Narratives of the Fall of Rome Mapped Onto America

Doctors to prescribe museum visits to help patients 'escape from their own pain'

She also had resources: Good health insurance, a supportive employer and close friends got her through. And research shows that resilience is about resources: What we receive from the outside is as important as what lies within us. Indeed, studies on women with chronic pain suggest that those who were most resilient were white women of significant economic means. Presumably these women are not worried about losing their homes, if they lose their jobs. They have access to the best medical care. They can arrange for transportation and for extra care,” she said. Thus, she said, “It’s important to remember that things like the availability of sick leave and how quickly aid comes in after a natural disaster and even whether a group is subjected to discrimination matters in terms of how people fare during difficult circumstances.”

“Therein lies the danger of the ‘inspiration’ story,” she said. “It lets us off the hook for interrogating the systems that are causing these problems. It elevates the individual – sometimes, at the expense of the group.”

KEY POINT

Women have the strength within themselves to become resilient and better manage their chronic pain, but access to resources can affect to how well one fares.

FIVE WORDS TO PUSH BACK AGAINST PAIN

Ms. Nicholson highlighted five concepts important to resilience:

1. **Pleasure.** Find what makes you feel good and hold on to it.
2. **Patience.** Pain is an endurance test, and you need to learn to be patient with yourself.
3. **Perseverance.** Find a way to make social contacts.
4. **Pause.** Take time out when you need to rest, and try and find those things that give you a sense of relaxation and stillness.
5. **Perspective.** Even with the most intractable chronic condition, there are always ebbs and flows. Holding on to the times that are better and remembering them is important, so you don’t feel like you’re just stuck in an unrelenting rut.

Figure 6: A First Sketch



Resilience can show up unexpectedly, Ms. Nicholson found. When she started to draw, Ms. Nicholson was amazed that she even had the energy to put pain to paper. She noticed sketching turned her focus outside of herself and awakened different parts of her brain.

FINDING YOUR VOICE

“Women in pain have basic rights. These include the right to be treated with dignity and respect, the right to disagree and the right to be heard.”

– **Penney Cowan**, founder and CEO of the American Chronic Pain Association

APPENDIX 1: AGENDA

Science, Innovation and Technology Summit: Chronic Pain in Women—Focus on Treatment, Management and Barriers

DAY 1: JULY 17, 2019

9:00 – 9:15 A.M.

WELCOME REMARKS

Elizabeth Battaglini, RN-C, CEO, *HealthyWomen*

9:15 – 9:45 A.M.

KEYNOTE PRESENTATION

Chronic Pain in Women: A Transformative Journey

Anita Gupta, DO, PharmD, MPP, *Professor, Rowan University School of Medicine and Senior Vice President, Heron Therapeutics*

9:45 – 10:15 A.M.

OPEN PLENARY

Sex, Pain and Death

Jeffrey Mogil, PhD, *Professor of Psychology, McGill University*

10:30 – 12:00 P.M.

SESSION 1: RESEARCH ADVANCES AND INNOVATIONS IN TREATMENT

Individual Differences in Pain Perception: The Need for a Personalized Approach

Roger Fillingim, PhD, *Distinguished Professor, University of Florida*

Molecular Mechanisms of Chronic Pain With a Focus on Migraine

Gregory Dussor, PhD, *Associate Professor, University of Texas*

Unmet Needs and Emerging Drugs for Chronic Pain

Srinivasa Raja, MD, *Director of Pain Research, Johns Hopkins Pain Treatment Center*

Technological Advances in Chronic Pain

Julie Pilitsis, MD, PhD, *Professor of Neurosurgery, Albany Medical School*

1:00 – 2:30 P.M.

SESSION 2: MANAGEMENT AND PREVENTION STRATEGIES

Application of Behavioral Strategies and Interventions for Pain Control

Michael T. Smith, MA, PhD, *Professor of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine*

Evidence-Based Efficacy of Noninvasive Nonpharmacological Approaches and Their Effectiveness in Treating and Managing Chronic Pain

Marie Hoeger Bement, MPT, PhD, *Associate Professor, Marquette University*

Importance of Self-Management in Chronic Pain

Yvonne D'Arcy, MS, APRN-C, CNS, FAANP, *Co-Chair of Pain Management Specialty Practice Group, American Association of Nurse Practitioners*

Role of a Strategist to Help Patients Improve Pain and Overcome Daily Frustrations

Lindsay Weitzel, PhD, *Migraine Strategist and Medical Writer*

2:40 – 4:10 P.M.

SESSION 3: BARRIERS AND CHALLENGES IN PAIN TREATMENT AND MANAGEMENT

Barriers to Providing Integrative Pain Care

Bob Twillman, PhD, *Clinical Associate Professor of Psychiatry, University of Kansas Medical Center*

Discuss Challenges to Pain Treatment Unique to Women

Mary Driscoll, PhD, *Associate Research Scientist, Yale School of Medicine*

Challenges Pregnant Women Face With Opioids—Gender Differences in Pain and Substance Use Disorders

Shruti Kulkarni, JD, *Attorney, DCBA Law & Policy and Board of Directors, Female Opioid Research and Clinical Experts (FORCE)*

Overcoming Health Care Challenges: Maneuvering Through Communication, Access and Cost Barriers While Dealing With Chronic Pain

Jaime M. Sanders, *Migraine Advocacy Patient Coordinator, GHLF/50-State Network; Patient Advocate/Blogger, The Migraine Diva*

4:20 – 5:20 P.M.

UPDATES FROM THE OFFICES OF WOMEN'S HEALTH

A Look at Pain, Opioids and the Influences of Sex and Gender

Kaveeta Vasisht, MD, PharmD, *Acting Associate Commissioner, Office of Women's Health, Food & Drug Administration*

NIH Pain Research in the HEAL Era: Enhancing Impact by Considering Sex as a Biological Variable

David Thomas, PhD, *Special Advisor to the Director, Office of Research on Women's Health, National Institutes of Health*

6:00 – 6:40 P.M.

DINNER & SPECIAL PROGRAM

"Finding Your Voice"

Penney Cowan, *Founder and CEO, American Chronic Pain Association*

Jenni Grover, *Founder and Author, ChronicBabe*

John Garrett and Cynthia Toussaint, *Co-Founders, For Grace*

Shoshana Lipson, *Founder of Migraine Facebook support groups and migrainemeanderings*

DAY 2: JULY 18, 2019

9:00 – 9:15 A.M.
OPENING REMARKS

9:15 – 9:45 A.M.
KEYNOTE PRESENTATION

Bias Against Women in the Treatment of Pain

Diane E. Hoffmann, JD, *Professor of Health Care Law, University of Maryland*

9:45 – 10:15 A.M.
OPEN PLENARY

Racial and Ethnic Disparities, Lived Pain Experiences and Stigma

Carmen Green, MD, *Professor, Anesthesiology, OB-GYN, and Health Management & Policy, University of Michigan*

10:30 – 12:00 P.M.
BREAKOUT SESSIONS

1:00 – 2:30 P.M.
SESSION 4: EFFORTS TO ADDRESS BARRIERS IN CHRONIC PAIN TREATMENT

Implementing the National Pain Strategy at the State Level to Improve Education About and Treatment of Chronic Pain

Cynthia Toussaint, *Co-Founder, For Grace*

Opioid Addiction in Women: Short- and Long-Term Implications

Kim Templeton, MD, *Board of Directors, American Medical Women's Association (AMWA)*

Breakthrough Solutions for Pain and Opioid Care

Elizabeth Ann Stringer, PhD, *Chief Science and Clinical Officer, axialHealthcare*

The Patient Voice in Pain and Development of Pain Therapeutics

Peter Pitts, *President, Center for Medicine in the Public Interest*

2:45 – 3:45 P.M.
BUILDING A ROADMAP TO BEST PRACTICES FOR CHRONIC PAIN TREATMENT AND MANAGEMENT

3:45 – 4:30 P.M.
SESSION 5: BRING ABOUT CHANGE THROUGH POLICY

Alicia Richmond Scott, MSW, *Designated Federal Officer, Pain Management Best Practices Inter-Agency Task Force, Office of the Assistant Secretary for Health, U.S. Department of Health & Human Services*

Ellen Blackwell, MSW, *Senior Advisor, Center for Clinical Standards and Quality, Centers for Medicare & Medicaid Services*

Cindy Steinberg, *National Director, Policy and Advocacy, U.S. Pain Foundation*

4:30 – 4:55 P.M.
CLOSING PLENARY

Pain, Resilience and How We Heal

Kate Nicholson, *Civil rights attorney, speaker and writer*

4:55 – 5:00 P.M.
CLOSING REMARKS

ACKNOWLEDGMENTS

HealthyWomen wishes to thank our panelists for their participation in the summit and for their thoughtful contributions based on their expertise in chronic pain in women. Please direct questions about the summit or this report to Monica Mallampalli, PhD, MSc, Senior Advisor, Scientific and Strategic Initiatives, HealthyWomen: Monica@HealthyWomen.org.

The Chronic Pain in Women Summit was made possible with support from Eli Lilly, Amgen, BIO and BD Biosciences.

Full recorded presentations can be accessed [here](#).

PLANNING COMMITTEE FOR THE CHRONIC PAIN IN WOMEN SUMMIT

- Valerie Bruemmer, MD, Clinical Research Physician, Eli Lilly and Company
- Penny Cowan, Founder and CEO, American Chronic Pain Association
- Jenni Grover, Patient Advocate and Author, ChronicBabe.com
- Kathleen Sluka, PT, PhD, FAPTA, Kate Daum Research Professor, University of Iowa
- Michael Walsh, Executive Director, Alliance for Balanced Pain Management
- Monica Mallampalli, PhD, Advisor, Strategic Development and Stakeholder Engagement, HealthyWomen
- Michael Miller, MD, Senior Policy Advisor, HealthyWomen

Writer: Debra Gordon, MS, Medical and Healthcare Communications, GordonSquared, Inc.

Designer: Sarah K. Hoctor Graphics



HealthyWomen's Chronic Pain Survey Executive Summary

Introduction

This report provides an overview of a HealthyWomen survey of women who experience and live with chronic pain. The survey aims to capture their views on how pain should be treated and managed, including the impact of chronic pain on their daily lives. We surveyed participants on:

- Pain cause and diagnosis
- Pain treatment
- Health care provider's treatment of pain
- Pain's interference with daily activities
- Access to information on pain

Methodology

A total of 1,004 respondents completed the online survey between May 23, 2019, and June 18, 2019. Respondents were reached via social media, newsletter and partner outreach.

Key Findings

- Of the 1,004 women who have experienced persistent or recurring pain for more than three months, 90 percent have received a diagnosis for the cause of their pain. Common causes of pain reported by respondents included arthritis, migraine, fibromyalgia, autoimmune diseases, pain related to surgery and spinal disc issues.
- Nearly half—48 percent—of respondents are treating their pain with opioids. The most common pain treatments, other than opioids, are other prescription medications, over-the-counter medications (like ibuprofen, aspirin, naproxen, acetaminophen) and physiotherapy (movement/exercise).
- Thirty-six percent of respondents don't think their health care provider (HCP) takes their pain seriously. Forty-five percent say their HCP is somewhat understanding, and 17 percent say their HCP is not understanding.
- Sixty-two percent of women sometimes feel hopeless and/or helpless about their pain, with 35 percent saying they always feel hopeless and/or helpless.
- Almost all respondents—95 percent—say their pain affects their ability to live a full and active life. And more than half (53 percent) say their pain interferes with their sleep.
- Thirty-eight percent of respondents think they do not have access to enough information about pain. The most popular positive changes women say they would like to see about how pain is managed are: adequately trained providers (65 percent), support from HCP (58 percent), and availability of resources (56 percent).



Pain is a very big deal.

REFERENCES

1. Institute of Medicine Committee on Advancing Pain Research, Care, and Education. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, DC: National Academies Press; 2011.
2. Fillingim RB, Gear RW. Sex differences in opioid analgesia: clinical and experimental findings. *Eur J Pain*. 2004;8(5):413-425.
3. Paller CJ, Campbell CM, Edwards RR, Dobs AS. Sex-based differences in pain perception and treatment. *Pain Med*. 2009;10(2):289-299.
4. HealthyWomen. Executive summary of HealthyWomen's chronic pain survey. https://www.healthywomen.org/sites/default/files/files/chronic_pain_survey.pdf. Published 2019. Accessed April 18, 2020.
5. Berkley KJ. Sex differences in pain. *Behav Brain Sci*. 1997;20(3):371-380.
6. Mogil JS. Sex differences in pain and pain inhibition: multiple explanations of a controversial phenomenon. *Nat Rev Neurosci*. 2012;13(12):859-866.
7. Bisgaard T, Klarskov B, Rosenberg J, Kehlet H. Characteristics and prediction of early pain after laparoscopic cholecystectomy. *Pain*. 2001;90(3):261-269.
8. Fillingim RB. Individual differences in pain: understanding the mosaic that makes pain personal. *Pain*. 2017;158(suppl 1):S11-S18.
9. Fillingim RB, Kaplan L, Staud R, et al. The A118G single nucleotide polymorphism of the mu-opioid receptor gene (OPRM1) is associated with pressure pain sensitivity in humans. *J Pain*. 2005;6(3):159-167.
10. Mogil JS, Wilson SG, Chesler EJ, et al. The melanocortin-1 receptor gene mediates female-specific mechanisms of analgesia in mice and humans. *Proc Natl Acad Sci*. 2003;100(8):4867-4872.
11. Holland PR, Akerman S, Andreou AP, Karsan N, Wemmie JA, Goadsby PJ. Acid-sensing ion channel 1: a novel therapeutic target for migraine with aura. *Ann Neurol*. 2012;72(4):559-563.
12. Yan J, Melemedjian OK, Price TJ, Dussor G. Sensitization of dural afferents underlies migraine-related behavior following meningeal application of interleukin-6 (IL-6). *Mol Pain*. 2012;8:6.
13. Burgos-Vega CC, Quigley LD, Avona A, Price T, Dussor G. Dural stimulation in rats causes brain-derived neurotrophic factor-dependent priming to subthreshold stimuli including a migraine trigger. *Pain*. 2016;157(12):2722-2730.
14. Avona A, Burgos-Vega C, Burton MD, Akopian AN, Price TJ, Dussor G. Dural calcitonin gene-related peptide produces female-specific responses in rodent migraine models. *J Neurosci*. 2019;39(22):4323-4331.
15. Rovner GS, Sunnerhagen KS, Bjorkdahl A, et al. Chronic pain and sex-differences; women accept and move, while men feel blue. *PLoS One*. 2017;12(4):e0175737.
16. Kumar K, Taylor RS, Jacques L, et al. The effects of spinal cord stimulation in neuropathic pain are sustained: a 24-month follow-up of the prospective randomized controlled multicenter trial of the effectiveness of spinal cord stimulation. *Neurosurgery*. 2008;63(4):762-770; discussion 770.
17. Slyer J, Scott S, Sheldon B, Hancu M, Bridger C, Pilitsis JG. Less pain relief, more depression, and female sex correlate with spinal cord stimulation explants. *Neuromodulation*. 2019. doi:10.1111/ner.13036.
18. Bonvanie IJ, Oldehinkel AJ, Rosmalen JG, Janssens KA. Sleep problems and pain: a longitudinal cohort study in emerging adults. *Pain*. 2016;157(4):957-963.
19. Harrison L, Wilson S, Munafo MR. Exploring the associations between sleep problems and chronic musculoskeletal pain in adolescents: a prospective cohort study. *Pain Res Manag*. 2014;19(5):e139-145.
20. Zhang J, Lam SP, Li SX, et al. Insomnia, sleep quality, pain, and somatic symptoms: sex differences and shared genetic components. *Pain*. 2012;153(3):666-673.
21. Holth HS, Werpen HKB, Zwart J-A, Hagen K. Physical inactivity is associated with chronic musculoskeletal complaints 11 years later: results from the Nord-Trøndelag Health Study. *BMC Musculoskelet Disord*. 2008;9:159.
22. Stolzman S, Bement MH. Does exercise decrease pain via conditioned pain modulation in adolescents? *Pediatr Phys Ther*. 2016;28(4):470-473.
23. Agency for Healthcare Quality and Research. *Noninvasive Nonpharmacological Treatment for Chronic Pain: A Systematic Review*. 2018. <https://effectivehealthcare.ahrq.gov/products/nonpharma-treatment-pain/research-2018>. Accessed April 18, 2020.
24. Vickers AJ, Cronin AM, Maschino AC, et al. Acupuncture for chronic pain: individual patient data meta-analysis. *Arch Intern Med*. 2012;172(19):1444-1453.
25. Centers for Disease Control and Prevention. *Guideline for Prescribing Opioids for Chronic Pain: Recommendations*. 2017. <https://www.cdc.gov/drugoverdose/prescribing/guideline.html>. Last reviewed August 28, 2019. Accessed April 18, 2020.
26. Hoffmann DE, Tarzian AJ. The girl who cried pain: a bias against women in the treatment of pain. *J Law Med Ethics*. 2001;28(suppl 4):S13-S27.
27. Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Am Med Womens Assoc* (1972). 2003;58(2):82-88.
28. Greene R, Stratton P, Cleary SD, Ballweg ML, Sinaii N. Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis. *Fertil Steril*. 2009;91(1):32-39.
29. Chen EH, Shofer FS, Dean AJ, et al. Gender disparity in analgesic treatment of emergency department patients with acute abdominal pain. *Acad Emerg Med*. 2008;15(5):414-418.
30. Michael GE, Sporer KA, Youngblood GM. Women are less likely than men to receive prehospital analgesia for isolated extremity injuries. *Am J Emerg Med*. 2007;25(8):901-906.
31. Green CR, Ndao-Brumblay SK, West B, Washington T. Differences in prescription opioid analgesic availability: comparing minority and white pharmacies across Michigan. *J Pain*. 2005;6(10):689-699.
32. Lamvu G, Soliman AM, Manthena SR, Gordon K, Knight J, Taylor HS. Patterns of prescription opioid use in women with endometriosis: evaluating prolonged use, daily dose, and concomitant use with benzodiazepines. *Obstet Gynecol*. 2019;133(6):1120-1130.
33. Huhn AS, Berry MS, Dunn KE. Systematic review of sex-based differences in opioid-based effects. *Int Rev Psychiatry*. 2018;30(5):107-116.
34. Wang X, Traub RJ, Murphy AZ. Persistent pain model reveals sex difference in morphine potency. *Am J Physiol Regul Integr Comp Physiol*. 2006;291(2):R300-R306.
35. Pattinson KT. Opioids and the control of respiration. *Br J Anaesth*. 2008;100(6):747-758.
36. Thompson T, Correll CU, Gallop K, Vancampfort D, Stubbs B. Is pain perception altered in people with depression? A systematic review and meta-analysis of experimental pain research. *J Pain*. 2016;17(12):1257-1272.
37. Smith PH, Homish GG, Leonard KE, Cornelius JR. Intimate partner violence and specific substance use disorders: findings from the National Epidemiologic Survey on Alcohol and Related Conditions. *Psychol Addict Behav*. 2012;26(2):236-245.
38. Vasilenko SA, Evans-Polce RJ, Lanza ST. Age trends in rates of substance use disorders across ages 18-90: Differences by gender and race/ethnicity. *Drug Alcohol Depend*. 2017;180:260-264.
39. Back SE, Payne RL, Simpson AN, Brady KT. Gender and prescription opioids: findings from the National Survey on Drug Use and Health. *Addict Behav*. 2010;35(11):1001-1007.
40. Mazure CM, Fiellin DA. Women and opioids: something different is happening here. *Lancet*. 2018;392(10141):9-11.

Pain is a very big deal.

healthy
women