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Pain

Pain is a significant symptom for more than half of individuals with multiple sclerosis. Within this population, pain falls under two different categories.

Referred to as neurogenic, the first type of pain can be a direct result of damage to the nerves of the central nervous system. With this type of pain, nerve impulses can go off-track or become over-stimulated and misfire, causing pain that can be lightning-like and intermittent, or can be a steadier burning, tingling, or tightening sensation.

Referred to as nociceptive, the second type of pain is associated with living with disability and its effects. This type of pain is caused by any mechanism that stimulates a pain response. Examples include muscle and joint pain, injection-site reactions, and pain related to urinary-tract infection, among several other causes.

Pain in multiple sclerosis is treated in a variety of ways, depending on the type and cause of the pain. Pharmaceutical management can include anti-seizure, anti-spasticity, anti-anxiety, antidepressant, and anti-pain medications. Complementary and alternative medicine (CAM) therapies such as acupuncture, acupressure, guided imagery, biofeedback, yoga, and tai chi may also help to relieve pain associated with MS.

Introduction

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More than 50 percent of individuals with multiple sclerosis identify pain as a significant symptom. For many years, the medical community did not support the idea that pain could be caused by the effects of multiple sclerosis, but physicians today recognize that pain is a common symptom.

Multiple sclerosis pain is mixed and may be divided into two different types. Pain from multiple sclerosis can be a direct result of damage to the nerves (referred to as “axons”) of the central nervous system (CNS), which consists of the brain and spinal cord. This first type of pain is referred to as **neurogenic**, and is caused by a lesion in the CNS. This type of pain may be intermittent or steady; spontaneous or evoked.

A second type of pain is associated with living with disability and its effects. This is referred to as **nociceptive**. Caused by any mechanism that stimulates a pain response, it can be mechanical, thermal, chemical, or electrical. Examples of this type of pain include musculoskeletal pain, lower-back pain, painful spasms, pain related to urinary-tract infection, pain of pressure sores, and even pain associated with disease-modifying drugs.

Neurogenic Pain

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This type of pain lies within the axons (nerves) of the CNS that are either inflamed or are malfunctioning after the protective layer of myelin has been damaged. Nerve impulses may go off-track and spread to adjacent damaged nerve fibers, or nerve cells may become over stimulated and misfire. This type of “nerve excitability” is irritating to the nerve cells within the brain and spinal cord, often causing sudden and sharp pain. The sensation can be lightning-like and intermittent, or it can be a burning, tingling, or a tight, “hug-like” feeling that can be continuous.

Surveys for patient pain indicate that the most common pain syndromes experienced in multiple sclerosis are: continuous burning in extremities; headache; back pain; and painful tonic spasms.

Examples of continuous multiple sclerosis pain syndromes include:

- Steady dysesthetic pain, which is a burning, tingling, or tightening sensation, usually occurring in the legs and arms, but sometimes in the body; it is the most common chronic pain syndrome; it can be dull, nagging, or have a prickling sensation associated with warmth; it tends to be worse at night and after exercise; it is also aggravated by changes in temperature
- Severe spasms and spasticity (muscle tightness caused by impaired nerve impulses)

Examples of intermittent multiple sclerosis pain syndromes include:

- Chronic headaches, experienced by up to one-third of patients; more than half (54 percent) report headaches as a symptom at the time of diagnosis; migraines are three-times more common in MS than in the general population; headaches are not associated with disability or lesion burden
- Lhermitte's sign, a shock-like sensation down the spine and legs when the neck is flexed; approximately 40 percent of individuals with multiple sclerosis experience this type of pain, although it usually does not require any treatment
- Optic neuritis, causing shooting pains in the eye
- Trigeminal neuralgia, a sharp facial pain brought on by a light touch or movement (occurring in roughly 2-to-5 percent of individuals with multiple sclerosis); up to one-third of these episodes can be bilateral (occurring on both sides of the face)

Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen usually won't work well on this type of pain. The over-stimulated nerves need to be calmed, and this may best be accomplished with anti-epileptic drugs, tricyclic antidepressants, and antispasticity drugs, to treat painful spasticity and spasms. Topical medications such as lidocaine gel or Zostrix® (capsaicin topical analgesic) may help reduce the burning and tingling. Optic neuritis is often treated with steroids to reduce the inflammation of the optic nerve.

Non-pharmaceutical strategies may help to reduce the perceived severity of the pain. More information about specific treatments is provided later in this section.

Nociceptive Pain

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This type of pain is usually less intense but can be long-lasting. For instance, weakness on one side of the body will cause someone to favor the other side and develop stiff joints; muscles can become twisted and cause the body to be unbalanced, frequently leading to muscle and joint pain. The same is true for spasticity (muscle stiffness) and spasms, as well as poor posture, with pain often occurring in the lower back. Even medications can sometimes cause painful side effects such as injection-site reactions, steroid-induced osteoporosis, and degenerative joint disease.

Unlike neurogenic pain, neuromuscular pain may respond to NSAIDs, which includes ibuprofen (Advil® and Motrin®). Tylenol® (acetaminophen) may help with this type of discomfort too. Antidepressants are sometimes effective and their function is twofold: they may help to shift the perception of pain, while also elevating one's mood (living with chronic pain is known to increase depression, fatigue, and anxiety). Anti-spasticity medications may be used if spasticity and/or spasms are contributing to one's discomfort.

Non-pharmaceutical approaches include acupuncture, massage, tai chi, yoga, meditation, hydrotherapy, and physical therapy, among others. A physical therapist experienced with multiple sclerosis can be particularly useful in returning balance and good posture back to one's movement. Warm compresses can sometimes loosen a tight muscle or reduce lower back pain, while an ice pack is normally prescribed for a recent muscle injury or injection-site reactions. More information about specific treatments is provided later in this section on pain with multiple sclerosis.

MS experts caution their patients about chiropractic care as it can potentially aggravate the nerves of the back and neck. If back pain is severe, tests should be done to see if a pinched nerve, slipped disc, or other structural problem is at fault.

Monitoring Your Pain

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The first step is to acknowledge your pain; only you know how severe and persistent it is. The key is to work with your doctor to develop a pain-management plan. Chronic pain can become a quality-of-life issue, affecting not only how you feel, but also how you live your life. If pain continues despite treatment, clients should ask to be referred to a pain center, specifically one that is experienced with treating individuals with MS and can offer a team approach.

Pain with multiple sclerosis is a complex problem involving many issues. Keeping a “pain diary” and verbalizing precisely how the pain feels, where and when it occurs, and what factors increase, decrease, or change the pain, are crucial to an accurate diagnosis and optimum treatment plan. With a pain diary, you will be able to share with your doctor specific details about your pain that you might not otherwise recall or realize. To follow are some guidelines to what your medical professional will want to know.

The acronym OLD CART is used in medical schools and nursing schools to assess pain:

- **O**nset – when did your pain begin?
- **L**ocation – where does your pain occur?
- **D**uration – how long do your painful episodes last?
- **C**haracter – describe how the pain feels, i.e., is it sharp, dull, aching, burning, tingling, throbbing, etc.?
- **A**ggravating [factors] – what makes your pain worse?

- **Relieving [factors]** – what makes your pain better?
- **Treatment** – what are you doing, using, and/or taking to relieve your pain?

Please note that a few variations of OLD CART are used, including “OLD CARTS,” which adds an S for Severity (to rate the severity of the pain on a scale from 1 to 10).

Pain is also assessed by function or Pain Effects Scale, which evaluates the impact of pain on one’s quality of life. Factors considered include the following:

- Mood
- Ability to walk and move around
- Sleep
- Recreation
- Enjoyment of life

Treatments for Pain

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A. DYSESTHESIAS

Dysesthesias are types of pain that are experienced as a burning or aching sensation. They are the most common types of pain seen in multiple sclerosis. The most frequently prescribed drugs used to treat this type of pain were originally developed as anti-seizure medications or antidepressants.

Pharmacologic Management

Anti-Seizure Agents, including (first-line, newer drugs) Neurontin® (gabapentin) and Lyrica® (pregabalin); (second-line) Tegretol® (carbamazepam) and Dilantin® (phenytoin)

Anti-Anxiety Agents, including Cymbalta® (duloxetine hydrochloride) and Klonopin® (clonazepam)

Tricyclic Antidepressants, including Elavil® (amitriptyline), Pamelor™ (nortriptyline), Norpramin® (desipramine), and others

As noted later in this section on pain, the drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) may sometimes be used as a “rescue” drug for burning dysesthesias.

B. TRIGEMINAL NEURALGIA

Trigeminal neuralgia is a “lightning-like” stabbing pain in the face. It is the result of damage to the trigeminal nerve, which innervates (provides the nerve supply to) the side of the face. Trigeminal neuralgia can usually be treated with medications such as anti-seizure agents.

Pharmacologic Management (These include anti-seizure, anti-spasticity, anti-anxiety, and anti-pain medications)

First line: Tegretol® (carbamazepine)

Second line: Oxtellar XR™ and Trileptal® (oxcarbazepine); Lamictal® (lamotrigine); and baclofen (formerly available as Lioresal®)

Other options: Dilantin® (phenytoin), Klonopin® (clonazepam), Depakene® (valproic acid), Lyrica® (pregabalin), Neurontin® (gabapentin), and intranasal lidocaine

As noted later in this section, the drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) may sometimes be used as a “rescue” drug for trigeminal neuralgia.

Surgical procedures

Surgical procedures to reduce pressure on the trigeminal nerve are possible in some situations.

C. LHERMITTE’S SIGN

Lhermitte’s sign is a brief, electrical sensation that occurs when the neck is bent forward. It moves from the head down the spine, and usually lasts for less than a second. It typically does not require specific treatment.

Non-Pharmacologic Management

Lhermitte's sign is seldom treated pharmacologically since it usually is not painful and tends to resolve on its own without any medications. New onset of Lhermitte's sign or a reappearance of Lhermitte's sign may indicate a presenting sign of a cervical cord lesion, or alternatively, a cervical cord exacerbation.

Pharmacologic Management

Lhermitte's sign is not typically painful and does not require pharmacological management, as the risk of side effects from medication does not outweigh the benefits. New onset of Lhermitte's sign or a reappearance of Lhermitte's sign may indicate an multiple sclerosis exacerbation (or a new or worsening cervical-cord lesion). If Lhermitte's sign is an indication of an multiple sclerosis relapse, your physician may discuss prescribing steroids or other relapse treatment. Acthar® Gel (ACTH given via injection) is another option for treating multiple sclerosis relapses.

D. BACK AND OTHER MUSCULOSKELETAL PAIN

Back and other musculoskeletal pain in multiple sclerosis can have many causes, including spasticity. Pressure on the body caused by immobility, incorrect use of mobility aids, or the struggle to compensate for gait and balance problems may all contribute as well. An evaluation to pinpoint the source of the pain is essential.

Non-Pharmacologic Management

A variety of strategies may prove helpful in managing musculoskeletal pain. These may include heat, massage, ultrasound, evaluation of gait and seating by a physical therapist, and treatments for spasticity.

A variety of relaxation techniques have proven helpful, as have acupressure and acupuncture. Acceptance and Commitment Therapy (ACT) may be of help. According to **GoodTherapy.org** (<http://www.goodtherapy.org>), ACT uses mindfulness skills to develop psychological flexibility and helps clarify and direct values-guided behavior. Mindfulness-based interventions include therapies such as behavioral activation, hypnosis, and relaxation techniques.

Pharmacologic Management

Tylenol® (acetaminophen), or non-steroidal anti-inflammatory drugs (NSAIDs) such as Advil® (ibuprofen), may be helpful in managing a variety of types of musculoskeletal pain. Individuals taking these pain relievers should check with their doctor and follow prescribing instructions. Too much of these medications can cause serious side effects, including liver damage.

Botox® (botulinum toxin) can be effective in treating migraine headache, which is common in multiple sclerosis. Botox also helps other pain, including pain from muscle spasms in multiple sclerosis.

Complementary and Alternative Medicine (CAM) Therapies

Readers are advised to consult their physician before trying any new treatment, including these types of CAM therapies.

Acupuncture has been studied as a possible therapy for a number of MS symptoms. Pain is the one symptom that has shown a consistent positive response to this approach, and it may be effective when provided by an experienced practitioner. The technique involves inserting and manipulating fine needles in specific points on the body. According to traditional Chinese medical theory, acupuncture points are located along meridians through which chi (vital energy) flows. There is no known anatomic basis for the existence of acupuncture points or meridians, but the technique may work in certain specific situations.

Acupressure is essentially a variation of acupuncture, but involves applying physical pressure to acupuncture points. As with acupuncture, the points to which pressure is applied may or may not be in the same area of the body as the targeted symptom.

Guided imagery is a meditative process focused on self-healing, relaxation, and self-awareness. It is a relaxation technique that is based on the concept that the mind and body function as a single entity, and may help manage stress and reduce tension.

Biofeedback involves measuring bodily functions such as blood pressure, heart rate, skin temperature, sweat gland activity, and muscle tension. In theory, this ultimately allows you to increase your conscious control of what are normally unconscious physiologic activities. By providing you with information about physiologic functions that are normally not perceived at a conscious level, it is believed by some to allow people to achieve control over these functions.

Both **yoga and tai chi** are based on traditional Asian medicine, and both have been shown to be of significant value in managing multiple sclerosis by allowing individuals to increase strength, flexibility, and balance. Several excellent books and videos are available that can help people develop a program that will assist in an overall management program for multiple sclerosis.

The medical use of **cannabis** (marijuana) is controversial since it has not been legalized nationally, but certain states have legalized its use by prescription through approved distribution centers. Studies with multiple sclerosis patients and cannabis for symptom relief are limited and the results have been mixed. In multiple sclerosis, cannabis is most often used to reduce the symptoms of pain and insomnia.

Additionally, there have been reports of adverse cognitive effects on people with multiple sclerosis. A recent report indicating that cannabis is associated with strokes in young people is also concerning. Your healthcare professional can help you to better understand the risks versus the benefits of cannabis in treating certain multiple sclerosis symptoms.

When Are Opioids Prescribed?

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With certain diseases and conditions involving severe pain that is not responsive to other drugs, opioids are a type of drug that is sometimes

prescribed. With multiple sclerosis, opioids are not as effective, and they are typically avoided. When these drugs are prescribed for any condition, doctors are cautious, as people become dependent upon them when used for a period of time. This is not a problem if managed correctly by the prescribing doctor, and when discontinuing the drug, care is taken to do so gradually. However, some people will abuse this type of medication.

What are opioids? Opioids are all related to morphine, and include such familiar brand names as OxyContin® and Percocet® (both are brand names for the drug oxycodone), and Vicodin® (hydrocodone). Several other related drugs are members of the opioid family, including morphine, which is marketed under the brand names of Astramorph® and Avinza®. According to WebMD, “Opioid analgesics suppress your perception of pain and calm your emotional response to pain by reducing the number of pain signals sent by the nervous system and the brain’s reaction to those pain signals.”

Heidi W. Maloni, PhD notes, “Opioids are used in multiple sclerosis pain, but not as a first-line drug. I will often use the weaker opioid-drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) as a “rescue” drug when the pain of trigeminal neuralgia becomes unbearable, or in cases of burning dysesthesias. I try very hard to avoid opioids.

“When are opioids indicated? When pain is moderate to severe, has significant impact on function and on quality of life, when non-opioids have been tried and failed, and very importantly, when the patient is agreeable to having opioids closely monitored, which may include signing a controlled-substance agreement, pill counts, and urine drug testing.

“A meta-analysis of opioid use in neuropathic pain from 1966 to 2004 indicated a significant effect on pain (reduction of 2 points on the Visual Analogue Scale) with those taking opioids compared to placebo. These were studies of short-term use. Use longer than six months has not been established from clinical trials. This means that in terms of treating neuropathic pain, the recommended efficacy and safety, abuse/addiction potential, and effects on quality of life, are not established. Three studies of

opioids in MS pain showed a poor response to opioids or a response only at high doses. Side effects include constipation, nausea, dizziness, and drowsiness.”

Chronic opioid use can alter brain chemistry and can cause more intense pain. One study concluded that only a minority of the patients with central pain due to multiple sclerosis responded to morphine and only at high doses. Neuropathic pain is poorly responsive to opioids. Routine use of strong opioids in multiple sclerosis was not recommended. (Kalman et al; *Eur J Pain*. 2002;6[1] study on opioids and pain).

Dr. Maloni explains, “Those experiencing multiple sclerosis pain have the capacity to accept and manage their pain. By becoming more active, as well as seeking human interaction and support, one’s perception of pain may be reduced. Using techniques such as mindfulness, along with a careful use of medications – such as using low doses of several medications, to avoid side effects of excess drowsiness and constipation – are important strategies to help individuals who are coping with multiple sclerosis pain.”

*Updated in October 2023 by Dr. Barry Hendin, MSAA Chief Medical Officer
Original content by Heidi W. Maloni, PhD, ANP-BC, CNRN, MSCN*

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