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REVIEW ARTICLE

Why Chronic Pain Patients are Misdiagnosed 40 to 80% of the Time?

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ABSTRACT

Researchers from Johns Hopkins Hospital have reported that 40%-80% of chronic pain patients are misdiagnosed. The leading causes for these errors are a failure to take a thorough and comprehensive history from the patient, and ordering the wrong tests. Typical testing errors are the use of anatomical tests to detect the physiological phenomenon of chronic pain, and a failure to understand the specificity and sensitivity of medical testing commonly in use.

Keywords: 3D-CT, Chronic pain, CRPS, Current perception threshold, Evidence based medicine, Facet blocks, Facet syndrome, Fibromyalgia, Fraud, Histrionic personality, Malingering, Misdiagnosis, Modic sign, MRI, Outcome studies, Provocative discogram, RSD, Roos, Root block, Thoracic outlet syndrome.

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INTRODUCTION

When a physician is evaluating a patient with chronic pain, there are several thought processes which ensue. The first question, which should be addressed, is the origin of the pain. Chronic pain has been variously described as a constant, as opposed to intermittent, pain which has lasted more than 3 to 6 months, so it is important to identify a condition which would produce this situation. Often, patients with disorders that have developed into a chronic pain situation have seen a number of other physicians without improvement. Therefore, the second concern which often arises is the veracity of the patient.

Various articles estimate fraudulent claims to range from 1 to 80% depending on unsubstantiated reports in the insurance literature.[1-4] This high index of suspicion has also permeated the medical literature, resulting in diagnoses of histrionic personality disorders, conversion hysteria, and malingering in patients who have routine tests, such as magnetic resonance imaging (MRI), computed tomography (CT), and X-ray, which are normal.[5]

However, there is another explanation for an undiagnosed chronic pain condition. A number of researchers from Johns Hopkins Hospital have published articles demonstrating that 40 to 80% of chronic pain patients are misdiagnosed.[6-10] For special diagnoses, these overlooked or erroneous diagnoses may reach levels of 92 to 97% for victims of electrical shock, or those mistakenly called fibromyalgia.[11,12]

There are two major factors causing misdiagnosis. An article from the **Wall Street Journal** quoted research from a 2013 study on 190 primary care patients. Physicians missed 68 diagnoses. The article attributes these oversights to two factors: (1) Doctors did not spend enough time with patients taking careful history and (2) doctors ordered the wrong tests.[13]

The question then becomes "What is the wrong test?" Physicians use anatomical test, when they should be using physiological test. A physician cannot take a picture of pain, because pain is a physiological condition. Physiology is defined as the study of how things function, such as stimulating an organism and measuring a response.

Anatomical tests are MRIs, CT, and X-rays, which merely take pictures. However, pain fibers are so small that their damage or compression cannot be detected by merely anatomical testing. Physiological tests are flexion–extension X-rays, provocative discogram, facet blocks, peripheral nerve block, indium 111 scans, bone scans, and root blocks, to name a few. These tests measure the activity of certain bodily functions, either by electrical or chemical means. Some of the most commonly misused and overused diagnoses and medical tests are listed below.

One of the most obvious misuses of a test is the X-ray. Upright cervical spine X-rays had neither predictive value nor correlation with the severity of pain an individual experienced.[14] Most patients with back or neck pain complain of pain when they lean forward or lean backward. Therefore, it would be logical to take X-rays while the patient is leaning forward or leaning backward, and not rely on upright X-rays. Yet clinical experience revealed that in patients who complained of pain with either flexion or extension or both, over 99% of patients seen

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at one clinic had only upright X-rays performed by the referring physician. Had flexion–extension X-rays been obtained, the physician would be able to note either of anterior or posterior dislocation of a vertebral body on another (anterolisthesis, or retrolisthesis) or a break of the pars interarticularis (spondylolysis) or the separation of a pars interarticularis break under mechanical stress (spondylolisthesis) or neural foraminal stenosis with extension which would not be visible in the upright or flexion film.

Clinically, a damaged disk presents as pain with motion, cough, sneezing, or bowel movements, either localized to a spinal segment or radiating down the path of a nerve root. For determining vertebral disk damage, MRIs do not do very well. Jensen et al did lumbar MRIs on 98 patients with no back pain and found that 27 had protruding disk (28% false-positive rate).[15] Additionally, Simmons and his group studied 164 patients with complaints of pain at various levels, requiring examination of several discs within a patient. They performed both MRI and provocative discograms (injection of a disc, while a patient is awake, and determining if the injection reproduces the pain the patient normally feels) on multiple disks in each patient. They found that for disks with negative discograms, 37% were reported as abnormal on MRI.[16]

Another anatomical assessment is vertebral body endplate signal intensity changes on magnetic resonance images. These are one of several findings a radiologist uses to diagnose degenerative disk disease and spondylosis of the lumbar spine. These signal intensity changes were first described and classified by Modic et al. Thompson and his colleagues found that Modic type 1 changes had a high correlation with a positive provocative discogram. The Modic type 1 vertebral body endplate change seen on MRI is described as endplate neovascularity, which is hyperintense on T2-weighted images and hypointense on T1-weighted images.[17] This radiological finding is often missed by less experienced radiologists.

Additionally, Braithwaite studied 90 patients using both MRI and provocative discograms. In the patients with positive provocative discograms, only 23% had Modic changes on MRI and 77% had no changes in MRI.[18] Therefore, he found a 77% false-negative rate for MRI. Sandhu and his group at Cornell studied 53 patients with severe neck pain using both MRI and provocative discograms. Of these patients, 79.5% with concordant pain on provocative discograms had no endplate changes (Modic) on T1 and T2 MRI images.[19] Therefore, in this study, the MRI had a 79.5% false-negative rate.

These studies confirm that MRI is of little use in determining which cervical or lumbar disk is damaged, since MRI has a 28 to 37% false-positive rate (28–37% of the time the MRI tells you something is wrong when there is nothing wrong) and a 77 to 79.5% false-negative rate (77–79.5% of the time, the MRI reports nothing is wrong, when there is something wrong).

The explanation for this type of error is simple. A disk is like a jelly doughnut, with the jelly being analogous to the nucleus pulposa and the doughnut portion being analogous to the annulus.[20]

The annulus has pain fibers in the rear one-third of doughnut portion surrounding the jelly. If the nucleus pulposa herniates into the rear one-third of the annulus, even without nucleus pulposa protrusion, this produces a pain that is exactly like a "herniated disk." This is called "internal disk disruption."[20]

A provocative discogram is a physiological test, where the rear one-third of the annulus is injected with saline, to see if this reproduces the pain a patient normally feels. If it does, this is considered a positive provocation. Then, an anesthetic agent is injected into the same needle to see if this eliminates the pain on a temporary basis. If it does, the physician has conclusive proof that this damaged disk is the source of the pain.[20]

Pain due to mixed motor-sensory nerve damage is in the distribution of the nerve and typically is accompanied by mechanical allodynia (pain to a normally nonpainful stimulus) and/or numbness. Electromyography (EMG)-nerve conduction velocity studies primarily measured damage to motor nerves. When viewed in cross section, 90% of the mixed motor-sensory nerves in the periphery are comprised of thick heavily myelinated motor nerves. Only 10% are the sparsely myelinated sensory nerves.[21] Therefore, it is very difficult to detect damage to sensory nerves using EMG-nerve conduction studies, because a loss of 10% of the electrical activity of a nerve, due to sensory nerve fiber damage, would not produce a significant change in the electrical activity of the nerve as recorded with nerve conduction studies. The sensory perception threshold test, which measures the small A delta, A beta, and C fibers, is a much better sensory test. These fibers respond to neurometer stimulation at 5, 250, and 2,000 Hz and respond to the Stimpod at pulse widths of 0.1, 0.3, 0.5, and 1.0 msec, both at 5 and 2 Hz.[22] Either of these tests should be used to detect sensory nerve damage, in preference to EMG-nerve conduction velocity studies.

Another overused test is the CT. Physicians mistakenly assume CT is as accurate for detecting bony lesions as the MRI is for detecting soft tissue injuries. However, research at Johns Hopkins Hospital shows that a three-dimensional (3D) CAT scan can detect pathology missed by regular CAT scan 56% of the time. In patients who have had previous surgery, the 3D CT

will detect pathology missed by the regular CT 76% of the time.[23] In fact, in a group of patients with normal CT and MRI findings who had been labeled "psychogenic pain patients," the 3D CT was able to detect previously unnoticed pathology and convert the diagnosis from a psychiatric one into a medical one.[24] It is surprising that the 3D CT is not more widely used, since the only expense in converting a regular CT into a 3D CT is the purchase of software package which costs $250,000. This certainly is well within the range of the average hospital or radiology center.

One of the most overused groups of diagnoses is sprains and strains. Sprains are defined as overstretching of the ligaments, the fibrous tissue which holds the bones together. Strains are defined as an overextension of muscle tissue, which is attached to the bone by the ligaments.[25] Sprains or strains should last no longer than a month. After that period of time, the problem is something other than a sprain or a strain. In fact, the Department of Health and Human Services of the US government has defined a strain as a disorder which causes an average of 7.5 days of restricted activity, 2 days of bed disability, and 2.5 days of work loss.[26] So any sprain or strain which persists beyond a month requires a more directed medical evaluation.

One of the most commonly missed diagnoses, often called a lumbar or cervical sprain or strain, is facet syndrome. The clinical features of this syndrome are back pain or neck pain worsened with extension, improved with extension, and diagnosed with facet blocks. Lumbar facet joint degeneration is a source of chronic low back pain, with an incidence of 15 to 45% among patients with low back pain.[27] On occasion, radiological studies may show facet hypertrophy. One study reported in association between heavy physical activity and the development of CT confirmed lumbar zygapophyseal joint osteoarthritis.[28]

A temporary facet block is given at the level of suspected pain, as well as the level above and below, since the innervation of the facet joint has input from three levels. A facet denervation is the treatment of choice. However, a recent publication reported that the efficacy of the steroid injection was equal to radiofrequency denervation.[27]

Patients are mistakenly told that they have complex regional pain syndrome or reflex sympathetic dystrophy (RSD) at an unconscionably high rate. The clinical presentation of RSD requires circumferential pain (pain all around a limb), in combination with mechanical and thermal allodynia (a painful response to a normally nonpainful stimulus). However, a number of patients present with pain in the distribution of the mixed motor-sensory peripheral nerves, without thermal allodynia. Research shows that these patients have nothing more than undetected nerve entrapment syndrome, but 71 to 80% of the time they were told they have RSD. These patients respond to a peripheral nerve block with 100% relief, and nerve decompression is their sole treatment[8,9] The incidence of a mixture of RSD and nerve entrapment occurs 26% of the time.[8] Both disorders need to be treated, using diagnostic blocks administered simultaneously, which then produces 100% relief, since a sympathetic block will have no effect on an entrapped peripheral nerve, and a peripheral nerve block will have no effect on RSD. Treatment consists of surgeries specific for each, i.e., nerve decompression for nerve entrapment and sympathectomy for the RSD. Unless both types of treatments are applied, the patient will continue to have pain. Only 3% of the patients who told that they had RSD actually had just this disorder.[8]

The differential test for RSD is simple and inexpensive – the Hendler alcohol swab test. Take an alcohol prep swab and drop alcohol on the affected limb, and blow on it. If the patient says this is painful, then the patient has thermal allodynia. Then swipe the affected limb with the alcohol swab. If the patient says this is also painful, then the patient has mechanical allodynia. Both thermal and mechanical allodynia need to be present in order to have the diagnosis of RSD.[8] The use of current perception threshold has also been of great assistance diagnostically, as has thermography.[21,29]

Another overused diagnosis is fibromyalgia. In research conducted at Mensana Clinic, 37 of 38 patients (i.e., 97% of the patients) who told they had fibromyalgia did not meet the diagnostic criteria.[12] The diagnostic criteria for fibromyalgia are very specific. The patient needs to have pain in at least 11 of 18 well-defined points in their body. Interestingly, these points overlap with common joint diseases, so that if a patient has pain in only three or four of the designated spots, the patient does not meet the diagnostic criteria for fibromyalgia. In the 37 so-called fibromyalgia patients, 133 other medical diagnoses, documented by objective medical test, were detected, which have been missed by the referring physician. These disorders range from acromioclavicular joint damage to Lyme's disease and included hyperparathyroidism, Hashimoto's thyroiditis, thoracic outlet syndrome, and psoriatic arthritis.[12]

Another commonly overlooked diagnosis is thoracic outlet syndrome. Typically, this type of injury occurs after a hyperextension injury, or repetitive trauma, from heavy lifting. The patient complains of numbness, tingling, or pain with the use of his arms, especially if used over his head. The pain and numbness is in the ulnar distribution, involving the last two fingers of the affected hand, but many involved all the fingers. Ninety percent of these cases are caused by compression of the brachial plexus between

the anterior and medial scalene muscle, with entrapment by the first rib beneath the brachial plexus. Only 10% of thoracic outlet syndrome cases have vascular compression.[30,31] The EMG-nerve conduction studies are of little use in trying to establish this diagnosis, because the distance across Erb's point is less than 5 inches, which does not produce reliable EMG-nerve conduction velocity study results.

Since the pathology of thoracic outlet syndrome is mostly neurological, or combination of neurological and vascular pathology, the best clinical test is Roos maneuver. A Roos maneuver consists of asking the patient to elevate their arms, with their elbows as high as their shoulders, and bent 90° at the elbow. The patient is then asked to hold that position for 2 minutes, and then asked what they feel in their fingertips. If the fingertips are numb, then this is a positive Roos test. The Adson maneuver consists of feeling the radial pulse and asking the patient to turn their head in the opposite direction. A diminution of the pulse is indicative of a positive Adson maneuver. Obviously, this maneuver detects vascular compression, which occurs less than 10% of the time in thoracic outlet syndrome, and even then it is unreliable.

However, when vascular compression does accompany thoracic outlet syndrome, the Roos maneuver is a better test than the Adson maneuver, as demonstrated by vascular flow studies with the arms up and arms down, in the bruise position, compared with the Adson maneuver. Over 80% of the time, vascular compression will be demonstrated by the Roos maneuver, but missed by the Adson maneuver. Again, as is true with all sensory nerve damage, the neurometer studies are useful for detecting sensory nerve damage and are especially valuable if the studies are conducted when the patient has their arms in the Roos position.[30,31]

All the above information can be confirmed by outcome studies. This is a valuable utilization of the concept of evidence-based medicine. Since chronic pain is a subjective experience, the most appropriate way to determine the efficacy of treatment is to measure a change in functionality. The quantifiable changes can be reduction in the use of medication, reduction in doctor visits, returning to work, and cost savings for medical expenses. Using the techniques just outlined, Johns Hopkins Hospital was able to save 54% on its workers' compensation costs. Using these techniques, one clinic has documented cost savings between $20,000 and $175,000 for long-term cases.

One of the most easily quantifiable parameters of recovery is return to work. The insurance industry reports that if a worker is injured on the job and remains out of work for 2 years or more, there is less than a 1% chance that he will return to work. However, when properly diagnosed and correctly treated, for this same type of patient, one clinic had a return to work rate of 19% for workers' compensation cases and 62% for auto accident cases, and a 90% reduction in narcotic medication and a 45% reduction in doctor visits.[32]

Additional outcome studies were published by Dr Long, who was chairman of neurosurgery at Johns Hopkins Hospital. His research group evaluated 70 patients, who had normal MRIs, CTs, and X-rays, and had been told that there is nothing to be done to help their neck pain and headaches. When the group utilized provocative discograms, facet blocks, and root blocks, they found that 44 of the patients (63%) were candidates for surgery. After surgery was performed, 93% of the patients reported improvement.[33]

The hallmark of a good evaluation for chronic pain is taking a careful and thorough history. This requires information about the location of the pain, in intimate detail. Pain in the arm will not suffice, without knowing which fingers are involved, or if the palm or the dorsum of the hand is involved. The type of pain (hot, sharp, burning, dull, cold, throbbing) determines the type of nerve fiber damage and the type of tissue affected. Knowing whether the pain is constant or intermittent, and if the latter, what makes it better or worse is also valuable. The severity of the pain has no diagnostic value and only serves to create contention between doctor and patient.

SUMMARY

- About 40 to 80% of chronic pain patients are misdiagnosed.
- The leading cause of misdiagnosis is (A) failure to spend enough time with a patient to take a careful history and (B) using the wrong tests, such as EMG, MRI, and CT.
- Correctly diagnosed and properly tested patients have documented improvement far in excess of current levels.
- A careful and thorough history is the best diagnostic tool there is.

REFERENCES

1. Ted, R.; Larrubia, E. Anti-fraud drive proves costly for employees. *Los Angeles Times*; Aug. 7, 2000. Available from: May 2013, http://www.harp.org/wc2.htm [Access Online]
2. Paul, LJ.; Markovitz, S.; Fahs, M.; Landrigan, P. Costs of occupational injuries and illnesses [Internet]. Ann Arbor: University of Michigan Press, 2000. pp. 195-197. Available from: http://www.press.umich.edu/16885/costs_of_occupational_injuries_and_illnesses
3. Workers' Compensation Notes, AFL-CIO Department of Occupational Safety and Health, Issue 3-00, May/June 2000. Page 1.
4. Peter, K. The price of health: employee fraud – a special report; vast amount of fraud discovered in workers' compensation

system. *The New York Times*, December 29, 1991. Available from: June 2013, http://www.nytimes.com/1991/12/29/us/price-health-employee-fraud-special-report-vast-amount-fraud-discovered-workers.html?pagewanted=all&src=pm
5. Hendler, N.; Talo, S. Chronic pain patients versus the malingering patients In: Kathleen, M.; Foley, MD.; Richard, M.; Payne, MD., editors. Current therapy of pain, p. 137-148, Toronto and Philadelphia: B.C. Decker Inc;1989.
6. Hendler N, Kozikowski J. Overlooked physical diagnoses in chronic pain patients involved in litigation. Psychosomatics 1993 Nov-Dec;34(6):494-501.
7. Hendler N, Bergson C, Morrison C. Overlooked physical diagnoses in chronic pain patients in litigation, Part 2. Psychosomatics 1996 Nov-Dec;37(6):509-517.
8. Hendler N. Differential diagnosis of complex regional pain syndrome. Pan Arab J Neurosurg 2002 Oct;6(2):1-9.
9. Dellon AL, Andronian E, Rosson GD. CRPS of the upper or lower extremity: surgical treatment outcomes, J Brachial Plex Peripher Nerve Inj 2009 Feb;4(1):1.
10. Long D, Davis R, Speed W, Hendler N. Fusion for occult post-traumatic cervical facet injury. Neurosurg Quart 2006 Sep;16(3):129-135.
11. Hendler N. Overlooked diagnoses in electric shock and lightning strike survivors. J Occup Environ Med 2005 Aug;47(8):796-805.
12. Hendler, N.; Murphy, ME.; Romano, T. Chronic pain due to other disorders misdiagnosed as fibromyalgia, abstract 1086. Available from: http://www.psychosomaticmedicine.org/misc/meetingAbstracts.shtml, March 2010.
13. Landro, L. (laura.landro@wsj.com). **The Wall Street Journal**, November 17, 2013.
14. Peterson C, Bolton J, Wood AR, Humphrey BK. A cross-sectional study correlating degeneration of the cervical spine with disability and pain in United Kingdom patients. Spine 2003 Jan;28(2):129-133.
15. Jensen MC, Brant-Zawadzki MN, Obuchowski N, Modic MT, Malkasian D, Ross JS. Magnetic resonance imaging of the lumbar spine in people without back pain. N Engl J Med 1994 Jul;331(2):69-73.
16. Simmons JW, Emery SF, McMillin JN, Landa D, Kimmich SJ. Awake discography: a comparison study with magnetic resonance imaging. Spine 1991;16(Suppl 6):S216-S221.
17. Thompson KJ, Dagher AP, Eckel TS, Clark M, Reinig JW. Modic changes on MR images as studied with provocative diskography: clinical relevance – a retrospective study of 2457 disks. Neuroradiology 2009 Mar;250(3):849-845.
18 Braithwaite I, White J, Saifuddin A, Renton P, Taylor BA. Vertebral end-plate (Modic) changes on lumbar spine MRI: correlation with pain reproduction at lumbar discography. Eur Spine J 1998;7(5):363-368.
19. Sandhu HS, Sanchez-Caso LP, Parvataneni HK, Cammisa FP Jr, Girardi FP, Ghelman B. Association between findings of provocative discography and vertebral endplate signal changes as seen on MRI. J Spinal Disord 2000 Oct;13(5):438-443.
20. Bogduk, N.; McGuirk, D. Pain research and clinical management. Vol. 13. Amsterdam: Elsevier; 2002. p. 121.
21. Raj P, Chado H, Angst M, Heavner J, Dotson R, Brandstater M, Johnson B, Parris W, Finch P, Shahani B, et al. Painless electrodiagnostic current perception threshold and pain tolerance threshold values in CRPS subjects and healthy controls: a multicenter study. Pain Practice 2001 Mar;1(1):53-60.
22. Tsui BC, Shakespeare TJ, Leung DH, Tsui JH, Corry GN. Reproducibility of current perception threshold with the Neurometer(®) vs the Stimpod NMS450 peripheral nerve stimulator in healthy volunteers: an observational study. Can J Anaesth 2013 Aug;60(8):753-760.
23. Zinreich SJ, Long DM, Davis R, Quinn CB, McAfee PC, Wang H. Three-dimensional CT imaging in postsurgical "failed back" syndrome. J Comput Assist Tomogr 1990 Jul-Aug;14(4):574-580.
24. Hendler N, Zinreich J, Kozikowski J. Three-dimensional CT validation of physical complaints in "psychogenic pain" patients. Psychosomatics 1993 Jan-Feb 34(1):90-96.
25. Bonica, JJ.; Teitz, D. The management of pain. Philadelphia: Lea & Febiger; 1990. p. 375.
26. Department of Health and Human Services DHHS # PHS 87-1592; 1987.
27. Lakemeier S, Lind M, Schultz W, Fuchs-Winkelmann S, Timmesfeld N, Foelsch C, Peterlein CD. A comparison of intraarticular lumbar facet joint steroid injections and lumbar facet joint radiofrequency denervation in the treatment of low back pain: a randomized, controlled, double-blind trial. Anesth Analg 2013 Jul;117(1):228-235.
28. Suri P, Hunter DJ, Boyko EJ, Rainville J, Guermazi A, Katz JN. Physical activity and associations with computed tomography-detected lumbar zygapophyseal joint osteoarthritis. Spine J 2015 Jan 1;15(1):42-49.
29. Uematsu S, Hendler N, Hungerford D, Long D, Ono, N. Thermography and electromyography in the differential diagnosis of chronic pain syndromes and reflex sympathetic dystrophy. Electromyogr Clin Neurophysiol 1981 Feb-Mar;21(2-3):165-182.
30. Empting-Koschorke LD, Hendler N, Kolodny AL, Kraus H. Tips on hard-to-manage pain syndromes. Patient Care 1990 Apr;24(8):26-46.
31. Dellon AL, Hendler N, Hopkins JET, Karas AC, Campbell JN. Team management of patients with diffuse upper extremity complaints. Maryland Med J 1986 Oct;35(10):849-852.
32. Hendler N. Validating and treating the complaint of chronic back pain: the Mensana clinic approach. Clin Neurosurg 1989;35:385-397.
33. Long D, Davis R, Speed W, Hendler N. Fusion for occult post-traumatic cervical facet injury. Neurosurg Quart 2006 Sept;16(3):129-134.