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There is No Such Thing as Adhesive Arachnoiditis Syndrome

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Abstract

Adhesive arachnoiditis syndrome is a proposed entity on an arachnoiditis support group website. A case is presented where the patient believed that all his maladies were attributed to this syndrome. The syndrome has not been vetted and is beginning to be acknowledged in the medical literature. The suggested features of this syndrome are reviewed and discussed as to why this entity is the antithesis of a syndrome. There is no such thing as adhesive arachnoiditis syndrome.

Keywords: Arachnoiditis, Fibromyalgia, Syndrome, Autoimmune Disease, Spinal Disorder, adhesive arachnoiditis syndrome

Abbreviations: Food and Drug Administration (FDA), computerized axial tomography (CT), magnetic resonance imaging (MRI), central nervous system (CNS), mixed connective tissue disease (MCTD).

Introduction

Adhesive arachnoiditis syndrome is a proposed entity by Dr. Sarah Smith on a support group website. **[1]** A syndrome is defined as: A group of symptoms that consistently occur together, or a condition characterized by a set of associated symptoms. The terms "syndrome", "disease" and "diagnosis" are often utilized improperly and ambiguously, compounding the complexities of medical knowledge.**[2]** Adhesive arachnoiditis syndrome is an example.

Case Report

I was asked to review a complex workers compensation claim resulting from an injury in 1989. The patient experienced sudden onset of back pain which was eventually treated with L3 and L4 laminectomy. There were some complications with MRSA infection of the surgical site. The surgery was not successful and corrective surgery was performed some months later.

Subsequent MRI scans demonstrated findings consistent with adhesive arachnoiditis. The patient had other complicating disorders prior to his injury, such as Protein C and Protein S deficiencies, as well as recurrent sinus infections most likely related to common variable immunodeficiency syndrome. Over the next 30 years, the patient developed additional complicated disorders and complaints such as presumed fibromyalgia, thromboembolic episodes, mixed connective tissue disease (MCTD), lupus anticoagulant, Sjogren's syndrome, chronic obstructive pulmonary disease, lichen planus, and a host of symptoms ranging from headaches, dental disease, diplopia, and hearing loss.

The patient produced a 9-page letter chronicling his 30-year disease history elaborating how it all was related to adhesive arachnoiditis syndrome, a direct result of the back surgeries he had in 1989. The patient claimed that all his hypercoagulable states, autoimmune states, and his general chronic diseases were related to adhesive arachnoiditis syndrome. Many of his treating doctors agreed with his assessment. The letter ended with a reference to an arachnoiditis support group website and a file produced by Dr. Sarah Smith.**[1]**

Discussion

Adhesive arachnoiditis is extremely rare and there are only 103 citations in PubMed. In the past 50 years only 1000 cases of chronic adhesive arachnoiditis have been reported in the worldwide literature. **[3,4]** MRI scans are considered the gold standard, however, Parenti et al published a series of 28 patients with lumbar arachnoiditis and found that MRI findings did not associate with the clinical features of lumbar arachnoiditis with few exceptions. **[5]** Physicians should be cautioned on assigning disability for lumbar arachnoiditis based solely on MRI findings.

There are no reported articles by Dr. Sarah Smith addressing adhesive arachnoiditis that could be found on PubMed. A literature search on adhesive arachnoiditis syndrome demonstrated no results. You can find a post by her under information on an arachnoiditis support group website where she makes her claims.**[1]**

So, what is adhesive arachnoiditis syndrome? I will attempt to summarize the many features as described.**[1]** According to Dr.

Smith: "Adhesive arachnoiditis presents with diverse symptoms, which may relate to problems outside the CNS, and could therefore be described as a syndromic picture. However, bearing in mind that the treatments used for the neurological symptoms may cause a variety of side-effects, it is difficult to say exactly which symptoms can be directly and solely ascribed to arachnoiditis and which are more complex in origin." **[1]** She goes on to proclaim that part of the problem is with the dismissal of symptoms as problematic. She claims patients have persistent and oftentimes bizarre pain complaints, tingling and numbness then launches into speculation about autonomic nervous system dysfunction that might be like that observed in reflex sympathetic dystrophy. She notes a variety of miscellaneous problems such as hypertension, dizziness, syncope, orthostatic hypotension, Raynaud's syndrome, hyperhidrosis, anhydrosis, fatigue, cognitive effects, side effects to medications, recurrent dental problems, headaches, auras, eye problems, burning mouth syndrome, dysphagia, osteoporosis, chest pain, recurrent sinusitis, weight gain, and dyspnea, to name a few.

Dr. Smith believes there are possible associations to autoimmune diseases without reporting any supporting evidence. She notes sufferers may experience symptoms or "flare-ups" of low-grade fevers, malaise, raised ESR, chills, lymphadenopathy, skin rashes, urticaria, angioedema, and photosensitivity. She further states: "A number of patients complain of dry eyes and mouth (as seen in Sjogren's syndrome) but this is likely to be due to side effects of medication in most cases. Other eye problems include iritis and uveitis. Patients may have a dual diagnosis of arachnoiditis and fibromyalgia (or chronic fatigue). It is likely that the features of myofascial pain and malaise are part of the arachnoiditis syndrome itself rather than a separate condition." **[1]**

Idris et al reported a case of fibromyalgia symptoms developing after the onset of arachnoiditis and this is the only published article that acknowledges this syndrome.**[6]** The referenced PDF file by Dr. Smith for adhesive arachnoiditis syndrome was deleted from the internet.**[7]** Idris et al in their discussion attempt to explain what adhesive arachnoiditis syndrome is, but never actually come to any conclusion and focused on fibromyalgia.**[6]** Fibromyalgia is a controversial disorder with an incidence reported between 2-4 % of the general population.**[8]** If a patient with adhesive arachnoiditis subsequently developed fibromyalgia, or fibromyalgia symptoms, with only 20 patients a year reported to have adhesive arachnoiditis in the world literature, fibromyalgia in this setting is likely unrelated to adhesive arachnoiditis. Based on statistics, there is no association that can be proven. If, however, a significant number of patients reported to have adhesive arachnoiditis were shown to develop fibromyalgia, then one could possibly make an association. Idris et al in assigning cause and effect of adhesive arachnoiditis and fibromyalgia have only focused on one declared component of the proposed syndrome and by unfortunately promoting this syndrome has added credence to its existence.

There was a case report by Kahan et al where a patient with long-standing MCTD developed idiopathic adhesive arachnoiditis. The authors believe that the MCTD may have predisposed the patient to developing arachnoiditis.**[3]** This case does not support the concept of adhesive arachnoiditis syndrome.

Dr. Smith's assertions are unfounded and speculative. She bases her conclusions on a survey of 66 patients which she claims have the diagnosis of adhesive arachnoiditis without providing any documentation; therefore, this is unpublished anecdotal data. Several questions arise:

1. With such a rare disorder, how was she able to collect and verify such a significant number of patients?
2. How does a survey alone determine a true association with adhesive arachnoiditis?
3. What percentages for each syndrome feature did her patient population experience?
4. Was any attempt made to remove from the syndrome list those patients with preexisting conditions or symptoms related to medication side effects, such as dry eyes (Sjogren's syndrome)?

Syndromes have specific, consistent features applied to presumptive patients to support a diagnosis of a specific disorder. Dr. Smith's descriptions are the antithesis of a syndrome. She does not claim any specific group of defining symptoms or clinical features but proposes such a wide range of complaints, disorders, and clinical findings that make it near impossible to exclude adhesive arachnoiditis syndrome from almost any clinical presentation with back pain, a multitude of complaints (see above) and definitive or questionable MRI findings. For patients frequenting the website, Dr. Smith has provided them with a buffet of symptoms and clinical findings they can collect and tabulate—with each one the weight of the diagnosis becomes more and more burdensome and convincing, resulting in absolute confirmation in their minds that they have this debilitating syndrome. In the worker's compensation claim, I presented here, the claimant and many of his treating physicians firmly believe that all his maladies are due to adhesive arachnoiditis syndrome. What we report in medicine has real-world consequences. This is not a vetted syndrome and should not be promoted in the medical literature. It places a tremendous burden on physicians and patients, particularly when attempting to determine disability.

Conclusion: There is no such thing as adhesive arachnoiditis syndrome.

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Conflict of interest: The author was an expert witness for the insurance company in the workers compensation claim described in the case report.

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