The Burton Report®

Lumbo-Sacral Adhesive Arachnoiditis
Introduction

There is no area of medicine today where greater, or more cruel suffering has been created in large populations of patients throughout the globe than those directly related to adhesive arachnoiditis of which the most common form is in the lumbo-sacral area. Whether due to sloth, disinterest, indifference or self-protective behavior by the medical, scientific and governmental communities lumbo-sacral adhesive arachnoiditis (LSAA) continues to remain essentially unknown, unreported, and unrecognized among both physicians and patients. An important reason for this state of affairs has been an organized deception and obfuscation regarding the oil myelographic substances Pantopaque® and Myodil® perpetrated by some of the originators and manufacturers of iophendylate for over half a century. This "bodyguard of misrepresentation" and "damage control" by company lawyers has, so far, insured that few, in positions of responsibility, have become adequately informed as a means of protecting the public interest.

Due to the failure of adequately propagating scientific information relating to LSAA it continues to be a serious world public health challenge continually being perpetrated on unsuspecting patients by their uninformed physicians. At the start of the new millennium the world has still not yet come to grips with this cruel phenomenon nor has it yet demonstrated an appropriate social conscience regarding this disease entity. Because of this LSAA continues to be a trail of tragedy for many unfortunate patients and new cases appear on a regular basis because of our failure to learn from history. This regrettable situation has tended to cast those health care professionals who have tried to sound the alarm in the role of "public foes" much like Dr. Peter Stockmann, the hero of Hendrik Ibsen's 1882 play "An Enemy of the People".

Even more remarkable is the fact that there are still some who actually insist that LSAA "does not exist ". Fortunately these individuals belong to the ever-diminishing circle of those who also believe that:

The Holocaust never happened.
Americans never really landed on the moon (it was staged).
September 11, 2001 was really an Israeli plot.

The saga of adhesive arachnoiditis is not just something of historical interest. In no area of medicine has failure of "informed consent" been more evident than in the continuing saga of this disease process. The discussion of this rather incredible and continuing misadventure, which focuses on the neurotoxicity of foreign body substances being introduced into the subarachnoid space for the purposes of myelography and epidural steroid administration, begins with a review of these subjects:

Myelography

Myelography, is an invasive diagnostic test in which a radio-opaque substance is placed in the subarachnoid space so that the space can be visualized by x-ray. The first contrast material used for this purpose was air. Air myelography developed from innovations in air ventriculography and air encephalography started in 1918, by Johns Hopkins neurosurgeon Walter Dandy. Because air was difficult to visualize on x-ray a search for alternatives began. In 1932 thorium dioxide (Thorotrast®) was first introduced. It appeared to be ideal for the purpose of myelography (and other diagnostic studies) and were it not for the fact that it was radioactive it would have been. Thorium dioxide turned out to

be a highly toxic radioactive substance. It was only 20-30 years after its introduction that the medical profession began to suspect that the sudden and unusually high incidence of malignancies involving the brain and spinal cord (as well as adhesive arachnoiditis) might be related to thorium dioxide's radioactivity. At this point this myelographic agent "fell into disuse".

Epidural Steroids

The "epidural" space is separated from the subarachnoid space only by the thin dura mater membrane and its associated filamentous pia mater. Epidural steroid administration is an empiric therapeutic modality commonly performed for the treatment of low back disorders. If the steroid is inadvertently injected into the subarachnoid space rather than the epidural space serious disability and incapacitation can result. Although all foreign body substances introduced into the subarachnoid space are "irritating" others can be highly neurotoxic. The most significant example of such neurotoxic agents are those containing ethylene glycols to allow for slow release (i.e. Depo-Medrol® , Depo-Medrone®, Aristocort® and Methylprednisolone Suspension®). When introduced into the subarachnoid space these materials can be highly neurotoxic and productive of a potentially disabling condition referred to as adhesive arachnoiditis. Since none of these steroids is approved, by their manufacturers, for epidural injection, and that they are clearly know to be toxic if misinjected, it is interesting to note that they still appear to be used by the majority of physicians now performing epidural steroid injections.

A prudent individual would assume that the medical leaders in performing, teaching, and publishing on epidural steroids would be acutely cognizant of the most potentially serious patient complication of "epidural" steroid administration. The facts suggest otherwise. A prominent medical publisher, publishing 16 spine-related patient manuals including "Lumbar Epidural Injection" and "Cervical Epidural Injection" has, under the section on "risks and complications", made no mention of adhesive arachnoiditis, the most serious potential complication of epidural steroid administration. This is despite the fact that new cases of incapacitating adhesive arachnoiditis directly related to inadvertent subarachnoid administration of neurotoxic steroids are being diagnosed by spine specialists on a continuing basis.

Are there alternatives to potentially neurotoxic formulations of methyl- prednisolone for epidural administration? Indeed there are. Why are they not used? The best answer is colossal ignorance, indifference, deception, or worse. Methyl prednisolone "suspensions" have neither "fallen into disuse" nor have they been officially identified as being a serious potential risk to the public health in any country at this time. What does this revelation mean in regard to informed consent? Might viewing Burton Report® allow patients to ask the right questions as to just which drugs will be injected and techniques used prior to therapy? Will physicians, because of these questions from informed patients, begin to modify their practice? We certainly hope so. It is sad to observe that once again, the public may be forced to call upon the good offices of the legal profession to help in promoting awareness of this clear and present danger because of failure by the health care establishment and elected officials to accept responsibility and become involved.

Intrathecal Catheters

The use of intrathecally placed (within the subarachnoid space) catheters for the purpose of delivering drugs (i.e. morphine for pain relief, baclofin for control of spasm) is not without risk of producing local adhesive arachnoiditis. These catheters can produce focal adhesive arachnoiditis, cysts and other inflammatory problems. That such risks exist should be explained to patients as part of the preoperative informed consent process. It should also be an important part of the risk versus benefit consideration for even considering such therapy in patients with normal life expectancies.

Summary

Clinically significant lumbo-sacral adhesive arachnoiditis is a particularly cruel disease because of the nature of the pain syndrome associated with it. Yet, its pathophysiology is well understood and is no mystery. Yet, for those desiring an objective determination of the existence or absence of adhesive arachnoiditis non-invasive high-resolution MRI scans have now allowed definitive determination of this frightening pathologic entity.

The nature of the pain associated with adhesive arachnoiditis is uniquely incapacitating and dolorologists have created the term "regional complex pain disorder" (RCPD) to describe it. Apologists for those who have created adhesive arachnoiditis and RCPD in patients have pointed out that only 1-5% of those with the condition actually have the

full-blown clinical symptoms (which can include progressive neurologic deficit and even death). The reason for this is interesting and appears to relate to the remarkable ability of the nervous system, with its great reserve and redundancy, to cope with severe insult and injury (if applied in a gradual fashion). It appears that despite being enmeshed in solid collagenous scar tissue and being deprived of the nurturing of cerebrospinal fluid and its normal vascular supply nerve cells can often achieve a tenuous equilibrium. This delicate balance can, however, be easily upset by additional insult or injury (i.e. spinal surgery or a motor vehicle accident releasing blood into the subarachnoid space).

There are a number of other neurologic parallels to the phenomenon of nervous system acclimization. One such is the "post-polio syndrome" where individuals afflicted with poliomyelitis early in life may make complete functional recoveries but as they age they experience progressive weakness. In this circumstance polio has destroyed the neuronal reserve and normal function belies the fact that there is no reserve. As the normal process of aging occurs and neurons die by attrition the lack of reserve is evidenced by the inability of the few remaining viable neurons to handle the challenge of normal function. The human body functions well with only one kidney, one lung etc. No one would dare to suggest that the loss of these organs was not inconsequential to the welfare of the individual. In the case of adhesive arachnoiditis the story has, unfortunately to date, been different.

Expressions of plight by individuals suffering with adhesive arachnoiditis are common. The many individuals legitimately suffering from adhesive arachnoiditis often are undiagnosed only because of healthcare establishment inadequacies. The legitimate disability of these unfortunates is then looked upon with distain by the medical and legislative communities who, because of their own diagnostic limitations, tend too often to consider these patients to be malingerers (or worse). The sad result of this are legions of patients seeking only the dignity of a definitive diagnosis from professional groups and organizations whose skill at evasion and cover-up have unfortunately exceeded their other talents. The disrespectful manner in which many countries have treated these unfortunates, whose only crime was not knowing the right questions to ask before a "minimally invasive" myelogram or epidural steroid injection was performed, has been sad to see.
Sadly, the rare examples where recourse has occurred typically has represented the compassion of the legal profession again serving as a societal "safety net". Even so legal attempts at legitimate recourse have been hampered by unrealistic "statue of limitation" requirements. Unfortunately, tort litigation reform has focused only on limiting the liability of transgressors so that their exposure becomes only a "business expense" and not something which will actually change their behavior.

The Editor, as a health care professional who has been concerned with the subject of neurotoxicity and patients suffering from adhesive arachnoiditis for over a quarter of a century has, as his only excuse for becoming involved in an issue emulating Hendrik Ibsen's "Enemy of the People", is not being "smart enough to know when to quit".

Adhesive Arachnoiditis
Frequently Asked Questions

Is Anatomic Arachnoiditis Common?

Yes, anatomic arachnoiditis (also termed "arachnoid adhesions or fibrosis") is something found, in some degree, in almost all adults but typically has no clinical significance. "Anatomic" arachnoiditis (also termed "arachnoid adhesions") is simply reflective of some degree of arachnoid inflammation having been present. This may result from minor infections involving the subarachnoid space or result from insult or injury (i.e. trauma, spinal surgery, etc.).

How does Arachnoiditis differ from Adhesive Arachnoiditis?

The difference between arachnoiditis and adhesive arachnoiditis is the same as that between a candle and a conflagration.

They are both fire but other similes exist. They differ in degree and intensity and the difference is quite substantial. A candlelit dinner represents fire as a friend. A conflagration represents fire as a foe.

Adhesive arachnoiditis is the end of the arachnoiditis spectrum. Adhesive arachnoiditis can carry the possibility of a lifetime of agony while arachnoiditis typically does not.

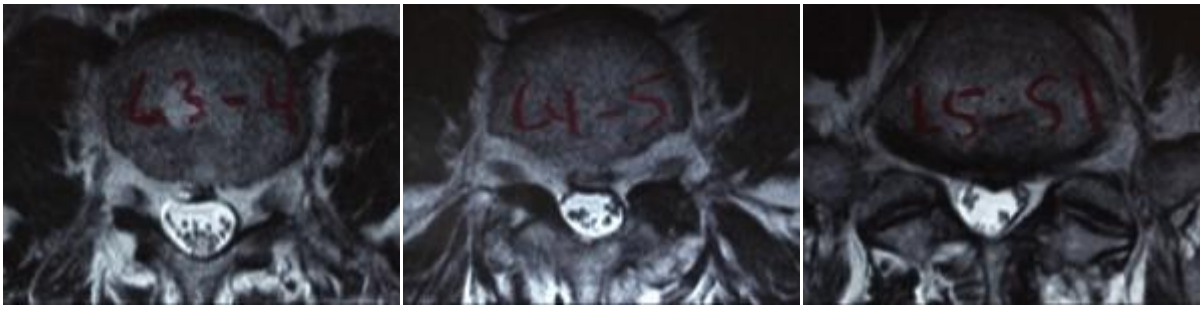
Conflagrations are usually disasters in real life. When the natural accommodative processes of the human nervous system fail and adhesive arachnoiditis becomes symptomatic it can then be a true disaster for the individual. The reason for this is that the agony (worse than pain) produced is constant and unrelenting. Sufferers are not even given the blessing of relief by a shortened life expectancy.

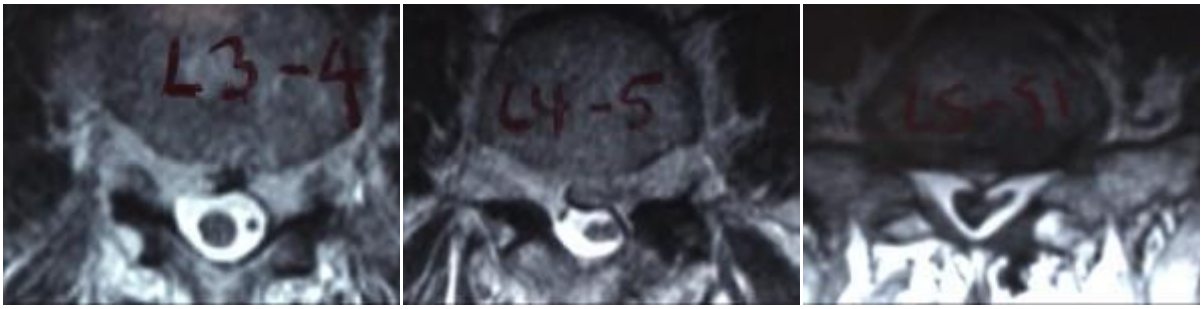
Today there are many thousands such sufferers who are old and frail. They need support and care and have only received disrespect from medical and governmental authorities who have implied that there is no such disease and that their problem is really "in their heads".

Why is it that the great majority of patients with Adhesive Arachnoiditis have no associated pain?

It is because of the remarkable ability of the human nervous system to acclimate to insult and injury of all types. Even though spinal nerves become enmeshed in scar tissue and deprived of vascular blood supply and cerebrospinal fluid nutrition they appear, in the majority of cases, after an initial period to be often able to reach a delicate equilibrium. For this to occur the inflammatory process has to be slow enough to allow the nervous system to acclimate. In LSAA the impaired nerves always have the potential for destabilization if additional insult occurs. This is a situation similar to the "post-polio syndrome".

How Fast Does Adhesive Arachnoiditis Develop?





Shown above are two sets of axial MRI images from the same patient taken over a period of seven months (comparable levels) during which he had a series of epidural steroid injections. In the first set there is evidence of some arachnoid adhesions. In the second set the arachnoiditis has progressed to Class III Adhesive Arachnoiditis.

If Patients with Adhesive Arachnoiditis Do Not Experience Associated Pain or Neurologic Deficit Has Harm Been Done?

The best way to answer this question is to provide a case in point:
It is horrendous, but true, that because of the dramatic world-wide increase in usage, and in value, human organs have become a commodity. Their harvesting is sometimes perpetrated on the unsuspecting. Many examples exist, typically in underdeveloped nations, where a "John" is lured into a House of Ill repute and awakens the next day somewhere else, in a tub of ice water, minus a kidney. If the individual is able to recover from this experience their kidney function should be normal because most humans can live normal lives with only one kidney. In the example provided has harm been done? Of course it has.

Under what circumstances does non-painful Adhesive Arachnoiditis become painful?

The nervous system does a remarkable job of using its great reserve to deal with adversity. It has been estimated that 97% of neurons serve as "reserve" during an individual's lifetime. It is because of this fact that recovery following a stroke (particularly in young people) can be so rapid and complete. Should this reserve be seriously compromised, in advance, the subsequent course is usually most different. The "punch drunk" prize fighter represents this situation where, over years, neuronal reserve has been lost and now the "bare bones" remainder is being compromised. In adhesive arachnoiditis the nervous system appears, in the majority of cases, to be able to maintain reasonable function despite the significant neuronal impairment produced. The delicate balance can be changed by subsequent events adversely influencing the existing delicate balance. Clinical experience has shown that the most common factor producing decompensation of the "steady state" leading to clinical symptoms is the introduction of blood into the subarachnoid space. Science has known since 1926 that blood, and its break-down products, can serve as foreign body substances and actually create, as well as potentiate, adhesive arachnoiditis. A common denominator in causing blood to be present is trauma. Clinical experience supports motor vehicle accidents and additional spinal surgery as being the most frequent circumstances causing this situation.

Why is the typical pain of Adhesive Arachnoiditis so disabling?

The pain (or agony) associated with adhesive arachnoiditis is particularly cruel and unrelenting. This adversity is particularly devastating because this disease, unlike others such as cancer, do not basically limit life expectancy. Nerves being deprived of nutrition become hyperexcitable and emit constant streams of nociceptive impulses to the brain. This type of abnormal afferent information is interpreted by the brain as being quite disagreeable in nature. This type of agony has a similarity to causalgia. Pain specialists (dolorologists) describe this type of condition as being an example of a "Regional Complex Pain Disorder".

What Surgical Procedures Have Helped in Treating the Pain of LSAA?

A really good surgical treatment for the pain of LSAA does not yet exist. Time has shown that when neurostimulators are implanted in carefully selected patients they can be a long-term blessing in allowing a return to a normal life. Direct surgical removal of scar tissue and attempting to revascularize the impaired nerves has not turned out to be worth the effort.

Are Implanted Morphine Pumps of Benefit in Treating the Pain of LSAA?

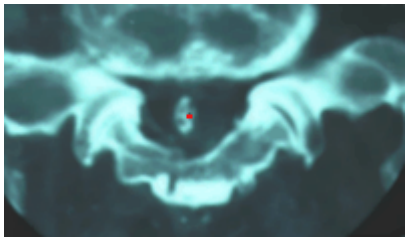
The basic issue of using chronic opioid therapy in pain patients is controversial, the issue of chronic opioid therapy in LSAA patients with pumps delivering morphine into the subarachnoid space is a *very* controversial issue. LSAA patients have true organic nociceptive pain (as opposed to neuropathic pain). Morphine pumps are expensive, require significant maintenance, and the subarachnoid catheters are prone to create arachnoid adhesions, cysts, etc, causing blockage and then requiring surgical revision. Patients become resistant to opioids (requiring ever-increasing dosages), they affect mental function, they often require additional drugs to control constipation, itching and somnolence. Opioids can produce significant alternations in respiratory, liver, endocrine, gastrointestinal, immune, nutritional and motor systems (Fox CD: Chronic Opioid Therapy: Another Reappraisal, Amer. Pain Soc. Bull., Jan/ Feb 2002). While implanted morphine pumps may be reasonable (risk versus benefit) for the patient with terminal cancer there is every evidence to suggest that in the LSAA patient the problems are much greater than the benefits.

Has Adhesive Arachnoiditis been the cause of unnecessary surgery?

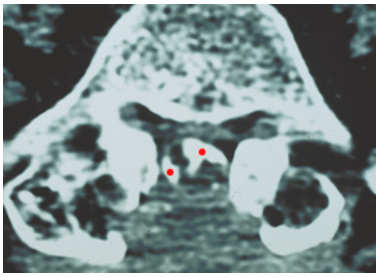
Indeed it has. One of the most appalling aspects of the use of neurotoxic materials such as iophendylate for myelography has been the misinterpretation of the scar from resulting adhesive arachnoiditis as being a "recurrent disc herniation" and leading to additional negative surgery. The histories of multiply operated-upon adhesive arachnoiditis patients is rife with the tales of negative additional explorations. All of this has served only to "muddy the water" regarding the basic culpability of the myelographic agent as being etiologic in the entire sad process.

Can Patients with Adhesive Arachnoiditis Develop Spontaneous Weakness or Loss of Bowel and Bladder Function?

Although this is uncommon the answer to the question is yes. Clinical experience has shown that the most advanced cases (Class III Adhesive Arachnoiditis) are prone develop these problems. This appears to be due to progressive calcification of the scar tissues as illustrated in the cases below.



In both CT scans the red dots are on areas of calcified adhesive arachnoiditis. In the example to the left the radiolucencies are actually nerve roots within the calcified mass. On the right the nerve roots are between the calcified areas.

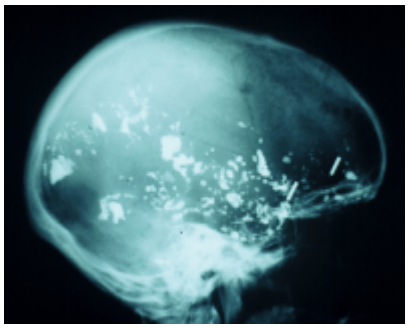


Can adhesive arachnoiditis cause death?

Cases have been reported where active lumbar adhesive arachnoiditis has progressed up the spine to the brain where the inflammatory process has caused blockage of the ventricular system, leading to hydrocephalus and death.

Can Adhesive Arachnoiditis Cause Constant and Intractable Headache?

When there is entry of neurotoxic agents into the subarachnoid space at the base of the brain the subsequent local adhesive arachnoiditis is capable of producing constant intractable headache.



This image shows the case of a patient who had a cervical Pantopaque® myelogram. The oil went into the base of the brain as well as the subarachnoid space over the brain hemispheres (as shown). This unfortunate individual developed a basilar adhesive arachnoiditis and associated intractable pain which was totally incapacitating.

Can Adhesive Arachnoiditis Cause Other Medical Problems?

Pain, spasm and neurologic abnormalities are the most common clinical problems associated with adhesive arachnoiditis. There are many other medical problems, such as autoimmune disorders, which have been attributed to this disease entity. Unfortunately this disease entity has been treated like an orphan by the medical, scientific, and governmental disciplines in the past and few studies have been carried out to clarify these serious problems.

Adhesive Arachnoiditis and Poisoned Medicine: An Editorial

Despite society's frequently professed concern with the sanctity of, and need for. the preservation of human life this attitude is not always evident when reality sets in. The melamine poisoning of pets by tainted foodstuffs has created a remarkable whirlwind of world attention which has resulted in a swiftly successful scientific investigatory response to find the culprits and make sure that this does not happen again.

Unfortunately, poisoned humans have not been as lucky as their pets. The press has also recently brought to our attention the fact that a syrupy poison (diethylene glycol, the prime ingredient in antifreeze) has been substituted for more expensive and safe ingredient glycerol in oral medicines, such as cough syrup throughout the world for over a decade.

The effect of the oral administration of diethylene glycol produces kidney failure, paralysis, and in most cases death (please note the similarity of symptoms with pet deaths due to melamine). Massive diethylene glycol poisonings have now been documented in Haiti, Bangladesh, Argentina, Nigeria, India, Panama, and China.

In underdeveloped countries most people who die don't come to a medical facility or have toxicological autopsy studies. While some may be tempted to take some solace in being in a more advanced society, they shouldn't. Please put on your seatbelts at this point in time.

You will no doubt be surprised to learn that the same poison, diethylene glycol, has been injected into the spine of unsuspecting

Americans and their European cousins since the 1940s as a ingredient of oil myelograms and continues to be injected today as an ingredient of steroid suspensions frequently being used to treat back pain.

When diethylene glycol gets into subarachnoid space it produces a chemical meningitis. This typically leads to adhesive arachnoiditis, which is severe scarring of the spinal cord and nerve roots. The most common symptom is constant and agonizing pain which is remarkably disabling. Many patients with adhesive arachnoiditis have taken their own lives as the only means of escaping their agony because adhesive arachnoiditis is rarely a direct cause of death.

The common use of diethylene glycol as a ingredient of steroid suspensions being blindly injected into the spine is a real, present, and serious public heath problem in the United States and Europe today. Remarkably there is no hue and cry evident. The sufferers are not infrequently told that the problem is "in their heads" when a high resolution MRI could provide the specific diagnosis.

Where are the medical and scientific professionals needed to investigate these tragedies? They are not in evidence. The only recourse a patient has today is in the medical-legal (if the statute of limitations hasn't run out) arena. The problem with this venue for society is that the settlements are not publicly propagated and the rest of the unsuspecting potential victims remain essentially uninformed. There just may be a slim chance, at this point in time, that the suffering of our pets from the melamine disaster might just possibly shift the spotlight a bit to the also not-wonderful-world of diethylene glycol.

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