

The New Zealand Ministry of Health
Report on Arachnoiditis

On February 25, 2002 The New Zealand Ministry of Health released a report commissioned by them to review the subject of arachnoiditis.

The report:

Arachnoiditis: A brief summary of the literature was developed at the Christchurch School of Medicine and Health Sciences, Christchurch, New Zealand by Peter Day and associates. This important document is available at:

./ <http://nzhta.chmeds.ac.nz/arachnoiditis.htm> .

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Supplementary Observations by Charles V. Burton, M.D.

Editor, Burton Report?

Reproduced from The Adhesive Arachnoiditis Home Page of the Burton Report (<http://www.burtonreport.com/InfSpine/AdhesArachHomePage.htm>).

This report, by Peter Day and associates at the Christchurch School of Medicine, prepared under the auspices of the New Zealand Health Technology Assessment Clearing House, is a landmark document.

This is the first time, in a century of global medical practice, that any government agency, in any country, has commissioned a report on this important subject.

The people of New Zealand, The New Zealand Ministry of Health and the Christchurch School of Medicine are to be complimented for having taken on this difficult challenge.

Any unbiased review of the subject of arachnoiditis is a difficult task because of the paucity of prior hard science on the subject.

Part of this problem has been a lack of awareness on the part of the medical profession in general as well as some of the medical reporting which has reflected hidden agendas and conflicts of interest not made apparent to their readers.

The foundation for legitimate health care planning is well-performed incidence and prevalence studies and data. Such have never yet been developed for this disease entity.

In a manner similar to that demonstrated by the tobacco industry, there has been an expenditure of many millions of dollars intended to obfuscate and provide “damage control” by the manufacturers of oil myelogram substances to thwart their being held responsible, in the legal arena, for their transgressions against the public.

This is also an important part of the history of the arachnoiditis saga. Today, many of the leading medical journals require full disclosure, by authors, of any real or potential conflicts of interest. These requirements were not in place when the literature reviewed by Day and associates was published.

Day and associates accurately point out the many limitations of the information they reviewed but also make the point that this information base "can produce valid results".

How "rare" is clinically significant adhesive arachnoiditis?

It has become clear that every person who has ever had a oil myelogram (i.e. lipiodol, pantopaque or myodil) has been left with permanent scarring of their pia-arachnoid membranes and some related impairment of cerebrospinal fluid production.

From the 1940s to the 1980s there were approximately 1 million oil myelograms performed each year throughout the world.

Scarring of the meninges secondary to exposure to these foreign body substances occurred in every single case.

How many of these situations progressed to the stage of advanced "chronic adhesive arachnoiditis" is simply not known.

The actual number of cases in which this inflammatory process ascended up the spine to the brain producing death is also not known. Sensitivity to inflammation is now known to a complex process involving issues such as the individual's own immunologic makeup.

It is readily apparent that although prevalence data is lacking the numbers of those afflicted with meningeal scarring is quite high. What then is the incidence of those individuals from this group who have become disabled by this condition (referred to as: "clinically significant adhesive arachnoiditis")?

What is "rare"?

It's meaning is different to each beholder. Long has estimated that 1% of those with adhesive arachnoiditis are "clinically significant". This editor believes that 5% is a more accurate estimate.

Why is the prevalence of chronic adhesive arachnoiditis so high and clinically significant adhesive arachnoiditis so low?

The answer to this enigma may very well lie in the remarkable ability of the human body to successfully deal with insult and injury if the progression of adversity is sufficiently slow.

This is particularly true of the nervous system.

This means that if the progression of an inflammatory process is sufficiently slow the nerves are then allowed to have the opportunity of surviving in their function despite progressive encapsulation with scar, progressive loss of vascular supply and progressive decrease in nutrition normally supplied by the surrounding cerebro-spinal fluid.

This also means that if the nerves are not allowed to have the opportunity of accommodating they then signal their distress to the brain by transmitting constant nociceptive information.

The nature of the resulting regional complex pain disorder is very often totally disabling to the individual.

This also means that many who have the scarring and are asymptomatic exist in a precarious state.

Additional insult can, in these cases, upset the balance producing decompensation and associated clinically evident problems. This type of situation is well known in medicine where large, benign, brain tumors progressively enlarge over many years and a minor incident (i.e. being struck in the head with a soccer ball) causes decompensation, unconsciousness, and

even death.

In the adhesive arachnoiditis cases the additional insult can be another myelogram, trauma such as a motor vehicle accident, or even an additional spinal surgery.

It is interesting to observe that clinically significant "chronic adhesive arachnoiditis" may be infrequent, or even "rare", compared to the huge reservoir of existing cases.

But it is also important to point out that even if these individuals appear normal they live with a "sword hanging over their heads" and are typically unaware of this liability.

It is also important to recognize that even if there is no apparent clinical problem significant bodily injury has occurred.

This is a situation similar to the "post-polio syndrome" where individuals afflicted with poliomyelitis at a early age loose many of their spinal neurons to the viral infection.

Many individuals appear to recover completely and clinical problems may only become evident later in life when the paucity of remaining neurons is diminished further by the process of aging, are no longer able to meet the needs of the body.

If it is a "rare" entity why should New Zealand, and the rest of the world, be concerned with "clinically significant adhesive arachnoiditis"?

There are few disease processes more cruel and disabling than adhesive arachnoiditis when it is "clinically significant".

The nature of the constant pain is such that it prevents normal activity, intellectual pursuits and

sleep.

Adhesive arachnoiditis does not affect longevity and sufferers do not the relative blessing of the limited life expectancy afforded by terminal cancer.

These individual are non-productive and require long-term supportive care.

It would have been nice to see that with the phasing out of oil myelography in the early 1980s that the issue of adhesive arachnoiditis would have become something of only historic interest.

This has not been the case.

The advent of epidural steroid injection as a primary treatment for back pain has created new populations of sufferers.

How rare is this?

Once again data on incidence and prevalence do not exist. In the United States the most reliable data on incidence are the number of physicians being brought to court by their patients.

This sad state of affairs seems to reflect only ignorance on the part of physicians and their patients as epidural steroid administration can (and should be) a safe procedure performed with appropriate informed consent.

What needs to be done?

As correctly noted by Day and associates scientific study and further assessment of this disease entity are required.

The most important role of this report, in my opinion, is being a first step in promoting awareness.

In 1968 ago a physician wrote a letter to the editor of the New England Journal of Medicine noting that whenever he ate at a Chinese restaurant he would experience symptoms similar to those of a heart attack.

Before long there were similar experiences shared by a multitude of other physicians.

The entity became referred to as "the Chinese restaurant syndrome";.

Investigation finally determined that a hypersensitivity to monosodium glutamate (MSG) and high salt content in the food appeared to be the etiology of this entity.

Only with increased awareness will physicians and patients begin to suspect, and then identify adhesive arachnoiditis. It should not be that a popular treatment for low back pain be allowed to create devastating disease for the patient.

How much is the prevention of this sad patient experience worth to a concerned health care system?

The importance of awareness.

In 1926 French neurologists Foix and Alajouanine published the description of a pathologic entity producing adhesions, spinal cord degeneration and paralysis.

We now appreciate that the Foix-Alajouanine syndrome probably represented a congenital arterio-venous malformation of the spinal cord associated with small intermittent bleeds producing local adhesive arachnoiditis, spinal cord restriction and impairment of blood supply producing myelomalacia, cavitation and neurologic problems.

This appears to have been the first medical description of adhesive arachnoiditis. If this something of only historic interest?

Recently the editor has become aware of a number of cases in which epidural injections for the purpose of analgesia were used to assist in childbirth in young and previously healthy women.

Following these injections the women developed severe, and in some cases permanent, neurologic problems. Subsequent imaging studies documented thoracic adhesive arachnoiditis.

Although these were standard epidural injections the anesthesiologists involved have been accused of producing the problem.

From reviewing the MRI studies I am convinced that these situations represented long-standing cases of clinically insignificant Foix-Alajouanine syndrome activated by the epidural injection (probably the included epinephrine) and thus becoming "clinically significant".

How many anesthesiologists know about the Foix-Alajouanine syndrome, adhesive arachnoiditis, or the dangers of injecting foreign body substances into the subarachnoid space?

This knowledge is truly a "rare" situation.

Appreciation to the New Zealand Ministry of Health

The literature review by Day and associates is a really important contribution, it is also something, which should have been done a long time ago by Health agencies in the United States or England.

New Zealand clearly has less resource available than these world neighbors. The fact that concerned citizens were able to reach the responsive ears of government to commission a valuable first-step technology assessment is exemplary and worthy of acknowledgement.

The editor's highest compliments and personal appreciation are extended to all involved.

The following excerpts: the Introduction and the Conclusions, from the NZHTA Report:
Day P. Arachnoiditis: A brief summary of the literature. NZHTA Report 2001.
2001New Zealand Health Technology Assessment Clearing House (NZHTA

Arachnoiditis: A brief summary of the literature

INTRODUCTION

This report is a brief descriptive summary review on arachnoiditis in the form of a background paper. A comprehensive and evidence-based systematic review of the literature is not presented here.

This review is a synthesis of information available in the literature that addresses the following: a summary of available literature, the nature and etiology of arachnoiditis, the characteristics of diagnosis, estimates of the prevalence and incidence of arachnoiditis, prognosis, treatment and future outlook for the condition, prevention, and arachnoiditis as a public health concern in New Zealand.

The report was commissioned by the Ministry of Health.

Conclusions

This brief descriptive review on arachnoiditis provides a summary of the available published peer reviewed literature:

- the nature and etiology of arachnoiditis
- the characteristics of diagnosis
- estimates of the prevalence and incidence of arachnoiditis
- the prognosis, treatment, future outlook and prevention of the condition
- and arachnoiditis as a public health concern in New Zealand.

The literature reviewed is multidisciplinary as the topic is broad and does not fit into one field.

Arachnoiditis is not well described in medical text books, disease classifications and diagnostic taxonomy systems.

From an evidence-based perspective the level and quality of evidence is generally lacking in the areas reviewed.

Important aspects of the nature, etiology, pathology, diagnosis, prognosis, treatment and demographics of arachnoiditis still remain either unknown or controversial.

Most of the specific literature is anecdotal clinical case studies and narrative reviews.

The general lack of specific material combined with the types of studies and small case series provide only weak evidence.

There is a major need for further research.

A substantial amount of literature, including several systematic reviews of controlled clinical trials, was identified in related topics, including epidural and intrathecal injection therapy and surgical intervention for the treatment of low back pain.

Other reviews and clinical controlled trials were identified in pain management literature related to analgesic drugs and their delivery and electro-stimulation of the spinal cord.

Literature was relevant but not specific, as the patient populations in these studies comprise a broad range of chronic pain diagnoses that may have included patients diagnosed with arachnoiditis.

Summary

Arachnoiditis is variously described in the literature. Radiological, experimental and pathological literature all describe arachnoiditis from differing perspectives.

Differing terminology has been used and has led to confusion over what should be termed arachnoiditis.

It is a non-specific inflammatory condition involving the leptomeninges and intrathecal neural elements.

Three distinct entities are generally recognised, arachnoidal adhesions, adhesive arachnoiditis and calcific arachnoiditis.

The term in the literature used for more clinically obvious and symptomatic forms is usually chronic adhesive arachnoiditis.

There is varied opinion over whether or not rarer and more extreme forms are the same disease or distinct entities.

The etiology of arachnoiditis is complex. Early literature showed arachnoiditis to be primarily a complication of infection but with the rise of antibiotic therapy this etiology has given way to more iatrogenic causes, primarily therapeutic complications from the treatment of lower back pain.

Chronic adhesive arachnoiditis is most commonly found in patients who have a history of a pre-existing back condition and have undergone multiple myelograms and multiple surgeries.

The multiplicity of procedures make it impossible to determine the single causative event in most patients.

Post-operative complications including arachnoiditis have been reported but studies with longer follow-up and extensive meta-analysis are required. Injection therapy for lower back pain has been implicated as an etiological factor but there is a lack of definitive evidence.

The relative importance of these etiological factors in the future is largely speculative.

Direct surgical inspection and radiology have provided objective evidence of arachnoiditis.

Newer non-invasive radiological technology has allowed for a greater degree of anatomical detail of the spinal meninges and surrounding structures.

The validity of radiological findings has been well established by opening the thecal sac and direct surgical inspection of the nerve roots.

Three distinct anatomical appearances are recognised; these are clumps of adherent nerve roots residing centrally in the thecal sac, nerve roots residing peripherally to the meninges giving an empty sac appearance and soft tissue mass replacing the sub-arachnoid space.

Attempts to correlate clinical signs and symptoms with radiological findings of arachnoiditis have produced variable results. The origin, type, location and distribution of symptoms in arachnoiditis patients are often atypical and present a complex clinical picture.

Pain is the most consistent symptom, particularly chronic severe back and/or lower extremity/leg pain. The pathological and radiological changes of arachnoiditis may be present in the absence of symptoms.

The clinical history in most arachnoiditis patients begins with presentation for back injury and back/leg pain.

Clinical investigation then most often includes multiple myelograms then laminectomy (often multiple) and sometimes spinal fusion.

Specific diagnosis for patients with repeated surgical failure are variously diagnosed with failed back syndrome, chronic low back pain, chronic pain syndrome or chronic-lumbar-spinal-adhesive-arachnoiditis.

Underlying diseases such as meningitis, recent herniated disc and spinal stenosis may all overlap with arachnoiditis.

While imaging techniques such as MRI of the lumbar spine have allowed for more and smaller abnormalities to be detected, the relationship between these and low back pain is somewhat controversial.

Some studies reported a high percentage of asymptomatic individuals who have never had

back pain or sciatica but showed abnormal myelograms, computerised tomography scans and MRI's. Dependence on MRI or CT alone could result in inappropriate clinical evaluation and intervention.

It is not possible to calculate the actual population-based incidence or prevalence of arachnoiditis in any form as the clinical data are not available.

The literature that is available tends to indicate that clinically significant arachnoiditis is rare.

Published estimates are anecdotal, varied and not generalisable to the population as the population at risk is also unknown.

Estimates of millions of cases have been postulated but these are unlikely given the number of cases actually reported and the estimates in the literature that are available.

Given the immense cost, the difficulties in clinical diagnosis and the relative rarity of the condition, demographic estimates of arachnoiditis will remain unknown.

The complete reliance on clinical experience coupled with the condition's rarity would seem to preclude it from demographic study.

There is a significant lack of literature dealing with the prognosis of arachnoiditis.

What few studies there are indicate that the prognosis of the condition is not strongly progressive nor is improvement evident in most cases.

Prognosis is complicated by the variable onset and spectrum of symptoms, difficulties in diagnosis and treatment, other underlying spinal pathologies and the ageing process.

Arachnoiditis is a complex neurogenic pain condition.

The exact relationship between anatomical arachnoiditis and pain has not been clearly documented.

Much of the literature on treatment other than specific surgical treatment is related to chronic non-cancer pain management and chronic back pain syndromes. These study populations are non-specific to arachnoiditis and include a wide variety of diagnoses.

Long-term effective treatments are difficult to achieve.

Therapy for arachnoiditis is palliative as it tends to relieve some symptoms, provide pain relief and give assistance with functional impairment but in most cases does not cure.

A regimen of medicine, physiotherapy, exercise and psychotherapy is recommended, providing a multidisciplinary pain management approach for arachnoiditis sufferers.

There are no specific therapeutic treatments best suited for arachnoiditis patients.

More research is needed with controlled clinical trials on patients with confirmed diagnosis of arachnoiditis.

The literature states the anti-convulsants gabapentin and phenytoin appear to have benefit.

Muscle relaxants such as baclofen and magnesium as well as the tricyclic anti-depressant venlafaxine may provide some pain relief.

The use of narcotic for chronics non-cancer pain treatment while providing pain relief remains controversial.

A degree of short-term pain relief provided by steroid injections or infusions can warrant their use despite the often high cost, and hazards of such treatments.

There is no one optimal analgesic method that is permanent.

Well designed clinical trials on the efficacy and safety of steroid injections and infusions are needed to better determine the benefits and hazards of their therapeutic role.

Technological advances have made spinal cord stimulation devices safer and less invasive.

There are indications of pain reduction in some arachnoiditis cases but there is remaining uncertainty over the benefits and long-term results of these treatments.

The pathological nature of arachnoiditis often presents as a possible indication for surgical intervention for pain, symptom and functional impairment relief.

This is mostly reserved for carefully selected patients as many patients also have underlying spinal pathologies.

Surgical intervention in patients with arachnoiditis remains controversial given its often surgically challenging nature and the potential benefits and risks of such treatment.

The outcomes from surgical intervention in published studies are generally poor providing only short-term relief.

Spinal surgery is recognised as an etiological factor in the development or exacerbation of arachnoiditis.

Standardised surgical treatment is not justifiable given the diversity of pathologies, symptoms, type and locations of pain and explains why surgical treatments have had such variable outcomes given a vast clinical spectrum.

It is unclear how coordinated and systematic research into arachnoiditis will proceed in the future given the relative rarity of the condition, the anecdotal nature of the literature and unresolved controversies.

New research into drug delivery systems and neural tissue recovery hold promise for arachnoiditis patients.

The continued advocacy of support groups and clinicians working in the area will remain an important impetus in future research.

Given the recognised iatrogenic etiology of arachnoiditis today, prevention will be an important part of any health strategy to address this condition.

The prevention of post-operative and post-injection complications are central to the prevention of new cases or the worsening of existing arachnoiditis in patients through reliance upon evidence-based clinical guidelines and conservative and multidisciplinary therapies.

The following table is also taken from the NZHTA Report 2001. It shows the reported procedure prevalence as at July 2001 of members of ASAMS, the Arachnoiditis Sufferers Action and Monitoring Society New Zealand.

Procedure Number of patients

Myelograms*

- oil-based dye	117
- water-based dye	64
- Epidural steroids*	50
- Spinal trauma	9
- Spinal surgery*	84

* Note: many patients will have had multiple procedures.

"New Zealand data were obtained on the numbers of persons registered with the ASAM Society as at May 1, 1999 and incomplete information for July 2001.

This data relates to voluntary registration and self-reported information and those who claim to have a definitive or suspected diagnosis of arachnoiditis in its various chronic forms."

Glossary from Lina

Etiology (aetiology) ... the cause(s)

Prevalence ... number of cases in a population

Incidence ... number of new cases per year

Prognosis ... future course and outcome

Evidence-based ... medical knowledge demonstrated by appropriately designed and executed

clinical trials, as opposed to →

Anecdotal ... observations of individual/small series of cases

Demographics ... distribution within a population

Analgesic ... pain-killing/ pain killer

Pathological ... nature of changes of diseased/abnormal parts of body, including microscopic changes

Leptomeninges ... arachnoid and pia membranes, enveloping the brain/spinal cord/spinal nerve roots inside the theca

Intrathecal ... inside the theca, the dural sac which holds the brain/spinal cord & first section of the nerve roots. Also contains the cerebrospinal fluid (CSF).

Iatrogenic ... caused by health professionals

Meta-analysis ... statistical method of investigating effect of individual factors in a complex situation that involves multiple factors