Arachnoiditis

A brief summary of the literature

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<th>Full Form</th>
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<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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<tr>
<td>CT</td>
<td>Computed Tomography</td>
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<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
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<tr>
<td>ICD-9/10</td>
<td>International Classification of Diseases 9/10</td>
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<tr>
<td>ASAMS</td>
<td>Arachnoiditis Sufferers Action and Monitoring Society</td>
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<tr>
<td>NZHIS</td>
<td>New Zealand Health Information Service</td>
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<td>US</td>
<td>United States</td>
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<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
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<td>DHB</td>
<td>District Health Board</td>
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Executive summary

Aim

The primary aim of this review was to provide a brief descriptive summary review of the literature on arachnoiditis and to synthesize available information to address the following topics:

- the available published literature in peer reviewed journals
- the nature and etiology of arachnoiditis
- the characteristics of diagnosis
- the prevalence and incidence of arachnoiditis
- the prognosis, treatment, prevention and future outlook of the condition
- the public health concern in New Zealand.

Literature search

The literature search was limited to major relevant bibliographic and review databases, clinical trials websites and websites specifically related to arachnoiditis. Arachnoiditis was searched as a subject heading and as a keyword in the title or abstract of any article. The search was limited to information in English from 1990 onwards. Exclusions included cerebral and optochiasmatic arachnoiditis, articles where arachnoiditis was an incidental finding not mentioned in the title or abstract, and animal studies.

Some 348 abstracts were identified from the search and relevant papers obtained. Additional relevant references cited by retrieved papers were also located where possible. Additional information was supplied by New Zealand governmental health organisations and patient support organisations.

Additional to the main searches, papers on low back pain, spinal surgery, intraspinal steroid therapy, radiology, and other issues related to arachnoiditis were sought for a broader overview. These overall search results cannot be considered to represent a systematic or comprehensive search and review. Multiple literature searches going back several decades combined with substantial evidence-based review and appraisal would be required to achieve this. No Health Technology Assessment (HTA) agency has yet done an evidence-based systematic review on arachnoiditis. (Such a review of arachnoiditis is likely to be difficult to focus and very general with non-specific recommendations).

Synthesis of material

Much of the specific arachnoiditis literature post-1990 is retrospective or before and after observational and case studies and narrative, non-systematic reviews. Studies are generally descriptive and anecdotal and relate to a small number of cases. The condition is not well described in medical text books nor disease classification and taxonomy systems. Patient support organisations host a range of Internet sites providing secondary reference material. A substantial amount of literature relevant to, but not specific to, arachnoiditis was identified, including some systematic reviews and controlled clinical trials. A broad range of chronic pain diagnoses are in these study populations, including patients diagnosed with arachnoiditis. This material included literature on the safety and efficacy of epidural steroid injection therapy for low back pain, back surgery, pain management and radiology.

The literature is varied in its descriptions of arachnoiditis and is medically speaking multidisciplinary. The topic is broad and does not fit into any one medical field. A notable weakness of this report is the reliance on the work of several key authors.

No attempt has been made to critically appraise the literature and assess study validity and generalisability in this report. From an evidence-based perspective the quality of evidence is lacking in the topic areas reviewed because of the lack of specific material, the study types and small case series. There is a major need for further research and the development of clinical trials.
Conclusions

The broad descriptive nature of the report, the scope of the literature search and the characteristics of the literature reviewed should be considered when interpreting the report conclusions.

- Arachnoiditis was variously described in radiology, experimental and pathology literature. 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 were generally recognised – arachnoidal adhesions, adhesive arachnoiditis and calcific arachnoiditis. The term in the literature used for more clinically obvious and symptomatic forms was usually chronic adhesive arachnoiditis. There was varied opinion over whether or not rarer and more extreme forms were the same disease or distinct entities.

- Early cases of arachnoiditis were mainly a complication of infection. Etiology today may be of iatrogenic origin through complications arising from the treatment of lower back pain. Patients often had a history of a pre-existing back condition and had undergone multiple myelograms and multiple surgeries. It was impossible to determine the single causative event in most patients, and there was a need for definitive evidence on the etiology of the condition. The relative importance of these etiological factors in the future was largely speculative.

- Direct surgical inspection and radiology provided objective evidence of arachnoiditis. Newer, non-invasive radiological technology allowed for a greater degree of anatomical detail of the spinal meninges and surrounding structures. Three distinct anatomical appearances were recognised – 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. Dependence on MRI or CT alone to detect abnormalities could result in inappropriate clinical evaluation and intervention.

- Attempts to correlate clinical signs and symptoms with radiological findings of arachnoiditis produced variable results. The origin, type, location and distribution of symptoms in arachnoiditis patients was often atypical. Chronic and severe back and/or lower extremity/leg pain was the most common symptom. Clinical history typically began with presentation for back injury and pain followed by clinical investigation, including multiple myelograms and surgery laminectomy (often multiple) and sometimes spinal fusion. Underlying diseases such as meningitis, recent herniated disc and spinal stenosis might all overlap with arachnoiditis.

- It was not possible to calculate the actual population-based incidence or prevalence of arachnoiditis in any form as the clinical data was not available. Estimates in the literature were anecdotal and variable and tended to indicate that clinically significant arachnoiditis was a rare event. The complete reliance on clinical experience coupled with the condition’s rarity would seem to preclude it from demographic study.

- There is scarcity of literature dealing with the prognosis of arachnoiditis. This indicated that the prognosis of the condition was not strongly progressive nor improvement evident in most cases. Prognosis was 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 and the exact relationship between anatomical arachnoiditis and pain has not been clearly documented. Much of the literature on treatment was related to chronic non-cancer pain management. These study populations included a wide variety of diagnoses. Therapy for arachnoiditis was 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 multidisciplinary regimen of pain management treatments was recommended.

- 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. Spinal cord stimulation devices provided pain reduction in some arachnoiditis cases but there was remaining
uncertainty over the benefits and long-term results of these treatments. Surgical intervention is reserved for carefully selected patients but remains controversial given its surgically challenging nature and the potential benefits and risks of such treatment.

- It is not clear how coordinated and systematic research into arachnoiditis will proceed given the relative rarity of the condition, the anecdotal nature of the literature and unresolved controversies. Support groups and clinicians working in the area will remain an important impetus to future research.

Prevention will be an important aspect of health strategies to address this condition given the recognised etiology which may have iatrogenic origins, particularly the prevention of post-operative and post-injection complications in patients through reliance upon evidence-based clinical guidelines and conservative multidisciplinary therapies.
**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.

**SUMMARY OF AVAILABLE LITERATURE ON ARACHNOIDITIS**

*The literature search*

The initial literature search was limited to major relevant bibliographic and review databases, clinical trials websites and websites specifically related to arachnoiditis. Arachnoiditis was searched as a subject heading in those databases where it was available and as a keyword in the title or abstract of any article. The search was limited to information in English from 1990 onwards. Documentation of the sources searched and the search strategies used is given in Appendix 1.

**Exclusions:**
- information on cerebral and optochiasmatic arachnoiditis
- articles where arachnoiditis was an incidental finding not mentioned in the title or abstract
- animal studies.

Some 348 abstracts were identified from the search and relevant papers obtained. Additional relevant references cited by retrieved papers were also located where possible. Articles in journals not available within New Zealand were not retrieved in full text.

Additional information was supplied by the New Zealand Ministry of Health, the Accident Compensation Commission (ACC), the New Zealand Health Information Service (NZHIS), the Arachnoiditis Sufferers Action and Monitoring Society (ASAMS) and Internet sites of other support organisations.

**Limitations**

Following the main searches, additional papers on low back pain, spinal surgery, intraspinal steroid therapy and other issues related to arachnoiditis were sought to give a fuller overview. These papers, however, cannot be considered to represent the results of a systematic or comprehensive search. Further multiple literature searches going back several decades, combined with substantial evidence-based review and appraisal, would be required to adequately cover the etiology, pathology, radiology, clinical aspects, prognosis and treatment of arachnoiditis. Individual searches on the possible etiology alone, would need to cover topics such as spinal surgery, myelography, epidural steroid injections, epidural anaesthesia, other intraspinal drugs, multiple lumbar punctures, spinal trauma, infection (meningitis), subarachnoid haemorrhage, spinal stenosis and chronic disc prolapse. No Health Technology Assessment (HTA) agency has yet done an evidence-based systematic review on arachnoiditis. Such a review of arachnoiditis is likely to be difficult to focus and very general with non-specific recommendations.
Much of the specific arachnoiditis literature post-1990 is in the form of retrospectives or before and after observational and case studies, narrative and non-systematic reviews, consensus statements and discussion papers. The observational and case studies are generally descriptive and anecdotal, and in many instances, relate to small numbers of cases. A significant volume of literature describing the characteristics and etiology of the condition is to be found in pre-1990 articles.

The largest case series in the literature is that presented by Long (1992), with some 321 cases of arachnoiditis identified in 3,500 chronic pain patients in the US. No specific prospective clinical controlled trials were identified. A small number of narrative and non-systematic literature review articles on arachnoiditis were identified. The condition is not well described in medical text books and disease classification and diagnostic taxonomy systems. Dr C.V. Burton’s chapter in Neurological Surgery (4th Edition 1996) was the only substantial reference identified. The only substantial book on the subject entitled Arachnoiditis: the Silent Epidemic by Dr J.A. Aldrete, a pain management physician based in the US, cites some 8,000 references. The work comprehensively describes the arachnoiditis condition, its etiology, diagnosis, therapeutic options and future prospects. Arachnoiditis/back pain/neurological support organisations host various Internet sites providing a huge array of secondary literature based on published information on the condition, particularly the etiology, symptoms and treatments.

Three Cochrane systematic reviews of a large number of controlled clinical trials were identified in the literature search as being relevant to, but not specific to, arachnoiditis. The topics of these reviews included injection therapy (steroids/anaesthesia) for sub-acute and chronic benign low back pain, surgery for degenerative lumbar spondylosis and surgery for lumbar disc prolapse.

Literature was identified on the controversy over complications of arachnoiditis arising from the oily contrast medium Myodil (iophendylate) introduced for ventriculography. A substantial amount of related, rather than specific, literature was identified on the more recent controversy over the safety and efficacy of epidural steroid injections, intrathecal steroid injections and spinal anaesthesia for the treatment of lower back pain or sciatica. A number of randomised controlled trials on the efficacy of these and other treatment interventions were identified. The efficacy and possible adverse effects of injection therapy including neurological complications such as arachnoiditis are discussed in this literature.

From an evidence-based perspective, the level and quality of evidence was mostly lacking in the areas reviewed. While observational and case studies, narrative reviews, discussions and consensus statements are likely to be prone to bias and methodological difficulties, they can produce valid results. The general lack of specific material combined with the study types and small case series that are published provide only weak evidence and their inappropriate use in answering questions dealing with causality is apparent in some instances. Works repeatedly cited by authors in the literature enabled key references to be identified. Studies not included were either not specifically relevant to the topic areas, contained very small case series, were articles held in overseas holdings or were letters or comment articles.

THE NATURE AND ETIOLOGY OF ARACHNOIDITIS

The nature of arachnoiditis

Arachnoiditis is well described in various forms in the literature. In 1992, Long published an extensive though non-systematic literature review on the pathogenesis, prognosis and treatment of chronic adhesive spinal arachnoiditis. This paper could be considered a definitive paper on arachnoiditis and has been often cited in related literature. It is also a significant reference for this report.

Early cases of arachnoiditis which were commonly associated with infection due to syphilis or tuberculosis are described in medical literature from the early 1900’s. Tuberculosis still accounts for cases in some countries. In 1909, Victor Horsley first recognised the disease entity “chronic spinal arachnoiditis”. Other pathological descriptions described localised cystic lesions beneath the pia.
Stookey in 1927, termed it “adhesive spinal arachnoiditis” and today the term “chronic adhesive arachnoiditis” is generally used to describe the disease entity (Long 1992).

Differing terminology and a lack of precise definition has led to confusion over how to define arachnoiditis. From a radiological perspective, literature has described minor variations in the sub-arachnoid space or blunted nerve root sheaths as arachnoiditis. From an experimental (animal and laboratory) perspective, inflammatory response to foreign substances in the sub-arachnoid space has been termed arachnoiditis. Descriptions of pathological processes in the literature have drawn particularly on animal studies. These descriptions range from simple adhesion and clumping of nerve roots to the complete adherence of the entire cauda equina into a single mass. The simple adhesion of nerve roots individually to the dura has produced an empty sac appearance and scarring. Its progression, binding nerve roots to themselves and to the dura, blocks cerebrospinal fluid. Extreme scarring obliterating the entire spinal canal or calcification of this to bone-like mass has also been described (Long 1992). Arachnoid cysts have been described, which are postulated to be caused by arachnoiditis, but this is difficult to prove (Kriss and Kriss 1997). Burton (1996), and others have attempted to define distinctive pathological stages of arachnoiditis. It can be divided into three primary entities: arachnoidal adhesions, adhesive arachnoiditis, and calcific arachnoiditis. There is debate over whether arachnoiditis results from the proliferation of arachnoidal membrane cells or inflammatory and fibroblastic cells. Minor degrees of inflammation or arachnoidal adhesions have little or no clinical significance nor do they produce symptoms. Long (1992), concluded that there is no evidence to suggest that the minor inflammation which often follows myelograms, surgery or trauma is clinically significant nor that it progresses to arachnoiditis. Although all degrees of inflammation could be termed arachnoiditis, the term reserved for more clinically obvious and symptomatic forms is usually chronic adhesive arachnoiditis.

Advanced and severe inflammatory forms of arachnoiditis have been identified in case reports. Though documented, they are forms rarely seen precluded by diagnosis of the precipitating disease. Opinion is varied over whether or not these are forms of the same disease or distinct entities.

Obliterative arachnoiditis has been described as severe thickening of the leptomeninges, reducing the sub-arachnoid space, sometimes encapsulating all of its contents. Arachnoiditis ossificans and pachymeningitis have been described as severe induration of the dural sac and its contents with a sometimes rubbery-like membrane including intradural calcifications (Aldrete 2000).

Syringomyelia has been described as the occurrence of cavitary lesions or long tubular cysts in the central nervous system usually communicating with cerebrospinal fluid compartments. This has been reported to be a secondary complication to arachnoiditis. Although the association between arachnoiditis and syrinx formation is known, the mechanism of syringomyelia is not well understood (Caplan et al. 1990).

Spinal stenosis is described as constriction of the spinal cord, which is followed by compression of neural structures. The association between arachnoiditis and spinal stenosis is not clear. The failure to properly recognise spinal stenosis probably inflates the true incidence of arachnoiditis. The presence of chronic thecal trauma may be implicated with arachnoiditis in association with spinal stenosis (Jackson and Isherwood 1994).

Summary

Arachnoiditis has been variously described in the literature from differing medical perspectives. It is a non-specific inflammatory condition involving the leptomeninges and intrathecal neural elements. Three distinct entities are generally recognised being arachnoidal adhesions, adhesive arachnoiditis, and calcific arachnoiditis. Today the term “chronic adhesive arachnoiditis” is generally used to describe the clinically significant form of the disease. Minor degrees of inflammation that could also be termed arachnoiditis have been shown to have little or no clinical significance nor do they produce symptoms. Opinion is varied over whether or not rarer and more extreme forms of arachnoiditis are the same disease or distinct entities.
The etiology of arachnoiditis

The etiology of arachnoiditis is complex. Early literature recognised arachnoiditis as a complication of infection. Tuberculous meningitis, syphilitic meningitis and also their intrathecal therapy are well documented causes. Arachnoiditis in these cases could also be highly progressive. By the 1950’s, the development of antibiotic therapy and the reduction of the risk of arachnoiditis due to infection led to the view that the incidence of arachnoiditis was linked to iatrogenic events, primarily therapeutic complications from the treatment of lower back pain (Shaw et al. 1978).

More recent literature is in agreement that the “syndrome” of chronic adhesive arachnoiditis occurs and that it is most commonly found in patients who have a history of chronic back pain and have undergone multiple myelograms and multiple surgeries. He comments that “because of the multiplicity of procedures, it is impossible to determine the causative event in most patients” (Long 1992).

The oily contrast mediums Myodil or Pantopaque (containing iophendylate), contrast agents used in myelography particularly, have been implicated in arachnoiditis. This is thought to be due to the irritant effects of the introduction of these substances into the sub-arachnoid space. The evidence for the effects of contrast agents used in myelography has been largely documented in animal experimental studies where much higher volumes than those injected into humans were employed. These studies revealed the occurrence of some degree of meningeal inflammatory reaction. The likelihood of severe inflammation appears to increase with repeated and poorly performed myelograms and myelograms associated with sub-arachnoid bleeding (Hughes and Isherwood 1992). Retrospective case studies have overwhelmingly concluded that rarely does contrast medium alone cause arachnoiditis (Shaw et al. 1978), (Rowland Hill et al. 1992). Few cases are reported from the millions of myelograms that have been performed. Patients with minor changes in nerve roots, scarring or contrast agent retention often have no symptoms (Long 1992). The true incidence of arachnoiditis due solely to the presence of Myodil or any contrast agent is unknown.

Lumbar disc lesions, their investigations and surgical treatments have been cited as important etiological factors in chronic adhesive arachnoiditis (Dolan 1993). Localised inflammatory reaction and a wide range of isolated sequelae have been reported after laminectomy, discectomy and spinal fusions. Longer follow-up and extensive meta-analysis need to be undertaken to better clarify the etiological association and risk of arachnoiditis (Aldrete 2000). Given the often complex patient history involving a pre-existing back condition, multiple myelography and multiple back surgeries, better evidence is required. Degenerative disease of the lumbar spine (herniation or degeneration) has been reported to cause arachnoiditis. However, the relationship of arachnoiditis with degenerative disease in the absence of spinal stenosis has not been clearly demonstrated (Jackson and Isherwood 1994).

Debates over the complications, as well as the efficacy of intraspinal steroid therapy (particularly Depo-Medrol containing methylprednisolone acetate) for lower back pain and various radicular syndromes including adhesive arachnoiditis, has led to a great deal of controversy in the literature.

An early literature review (Wilkinson 1992), while outlining the pros and cons of such therapy, says there is a need for definitive studies on the neurotoxicity of intraspinal steroid preparations. Several studies in this non-systematic review implicated Depo-Medrol as a potential cause of arachnoiditis. Most of the evidence was circumstantial and followed multiple, large dose, or frequent injections.

A later systematic review of complications associated with epidural steroid injections concluded that there were few published studies of serious complications following the procedure. The few reports noting complications concerned patients receiving multiple injections over a prolonged period of time (Abram and O’connor 1996). The authors found no reports of arachnoiditis in 64 series with nearly 7,000 patient cases.

A more recent non-systematic review, concluded that epidural medications may not remain confined to the epidural space and inaccuracies in placement approach 40%. Steroid formulations may be neurotoxic when injected intrathecially but further research is needed. Serious permanent complications, including arachnoiditis to the spinal cord and nervous system, are “a rare but certain risk” (Nelson and Landau 2001).
A Cochrane systematic review on the efficacy of injection (steroid and anaesthetics) therapy for chronic low back pain included reference to adverse outcomes including arachnoiditis (Nelemans et al. 2001). This concluded that from the 21 RCT’s evaluated, few adverse events were reported. Because of the lack of definitive evidence either way, or the lack of well designed trials, a solid foundation for the effectiveness of steroids is lacking.

Summary

The lack of high quality evidence and the inability to adequately control for other factors known to be associated with arachnoiditis, complicates the defining of the exact etiology of the condition. Early literature showed arachnoiditis to be primarily a complication of infection but given the rise of antibiotic therapy this has given way more to iatrogenic causes. Literature from the 1940’s implicated oil-based and to a lesser extent water-based myelographic contrast agents with arachnoiditis. The typical patient often had a history involving multiple therapeutic interventions including multiple myelograms and back surgeries. Today however, many patients present for back surgery on the basis of non-invasive CT or MRI without myelography. Thus, the etiology of arachnoiditis in the future is likely to be a post-surgical complication if myelograms gradually disappear. However, other underlying spinal pathologies such as degenerative disc disease, disc herniation, and spinal stenosis have been associated with arachnoiditis. Injection therapy has been implicated but the lack of definitive evidence either way is evident. Just how important these respective etiological factors will be in the future is largely speculative. The incidence of clinically significant “chronic adhesive arachnoiditis” is small and the literature describes this as a rare condition.

THE CHARACTERISTICS OF DIAGNOSIS

Other than direct surgical inspection, radiology has provided objective evidence of arachnoiditis. Radiological modalities have changed over time allowing increased detail of the spinal meninges and surrounding structures. Plain radiology was followed by myelography in the 1920’s, followed by computed tomography (CT) in the 1970’s, and MRI in the 1980’s. Myelography allowed for the assessment of the contours of the arachnoid space, the roots of the cauda equina and to some degree, the flow and abnormal flow of contrast agent. Cross-sectional imaging with CT, especially with myelography and also MRI, presented more detail of the thecal sac, root sleeves and cauda equina (Petty et al. 2000).

Radiological changes on the basis of myelographical findings included nerve root clumping, contraction, thickening and empty appearance of the thecal sac through peripheral adhesion of nerve roots and shortening and blunting of perineural sheaths. The validity of these findings has been well established by opening the thecal sac and direct surgical inspection of the nerve roots (Jackson and Isherwood 1994). Repeat appropriately performed myelography, it has been argued, is the best way to gauge the extent and severity of the sub-arachnoid scarring process (Long 1992).

MRI has become the diagnostic test of choice for imaging evaluation of the spine given its non-invasiveness and the greater degree of anatomic information available with axial and sagittal views (Gundry and Fritts 1997). This is well described in the literature. MRI findings defining radiological changes in arachnoiditis have correlated well with myelography, with a sensitivity of 92%, specificity of 100% and accuracy of 99% (Ross et al. 1987). In another study, MR appearances of arachnoiditis were compared with, and correlated well with, CT myelography and plain film myelography and were classified into three groups (Delamarter et al. 1990). The first group showed clumps of adherent nerve roots residing centrally within the thecal sac. The second group showed nerve roots peripherally to the meninges, showing an empty thecal sac appearance. The third group showed soft tissue mass replacing the sub arachnoid space. These findings were based only on anatomic appearance and do imply pathological change. No attempt was made to correlate arachnoiditis with clinical symptoms or types and timing of previous procedures.

The clinical syndrome of arachnoiditis has been described in the literature but no standard clinical picture has emerged. Authors in major papers describing the symptoms of arachnoiditis are varied in their descriptions, none can be considered typical for arachnoiditis, no consistent clinical pattern is
evident in patients, “no two cases are alike either in the time lapse before symptoms or in the distribution of the syndrome pattern” (Bourne 1990).

Typically chronic severe back and/or lower extremity/leg pain is evident, characteristically it is “a constant and burning nature”, usually with “a poorly localised, paleospinothalamic pain pattern that is diffuse in nature” (Burton 1996). Pain is the most consistent symptom in those patients “where strong circumstantial evidence exists” for chronic adhesive arachnoiditis.

The clinical history in most patients begins with presentation for back injury and back/leg pain. Clinical investigation most often includes multiple myelograms then laminectomy (often multiple) and sometimes spinal fusion. Some may not improve and beyond a specific diagnosis for recognisable tuberculosis and syphilitic arachnoiditis and rare forms of meningitis, patients are variously diagnosed with “failed back syndrome”, “chronic low back pain”, “chronic pain syndrome” or “chronic-lumbar-spinal-adhesive-arachnoiditis” (Petty et al. 2000). These overlapping labels, argue the authors, make it tempting to label patients as being diagnosed with arachnoiditis, which may be apparent from a radiological perspective but cannot be assigned a specific clinical syndrome.

In his 25 years of clinical experience, Long (1992), described symptoms in patients such as chronic back (94%) and leg (81%) pain, motion impairment (91%), chronic muscle contractions secondary to surgery (94%), motor loss (74%) and sensory loss (81%) and reflex changes (96%) based upon the largest published case series of 321 patients with arachnoiditis. Of this series for 1.8% of patients the syndrome was considered progressive, 1.2% were wheelchair bound but 92% had limitations on the distance they could walk.

Arachnoiditis is not well described in medical text books, disease classification and taxonomy systems. The ICD-9/10 system includes arachnoiditis under meningitis of other unspecified cause. Other codes related to infectious meningitis, neuritis and radiculitis and unspecified lumbar cord injury could also possibly be used but these are not specific codes (see Appendix 2). The taxonomy of chronic pain syndromes does not include a specific diagnostic description of arachnoiditis (Merskey et al. 1994). Other pain conditions are described in which this condition could be included. Conditions described as lumbar spinal pain attributed to infection or after failed back surgery are included under lumbar spinal or radicular pain syndromes. The diagnostic description includes pain of unknown origin despite surgical intervention attempt(s) which complicate patients pathologically and psychologically; until reliable diagnostic techniques are available conjecture remains over the possible origins. Other conditions related to arachnoiditis are described such as the syndrome of syringomyelia and spinal stenosis: cauda equina lesion.

Data from the 1999 Arachnoiditis Survey of sufferers with a diagnosis of arachnoiditis showed that of 317 respondents, 58% reported at least one oil-based myelogram, 61% epidural steroid injection, 74% spinal surgery and 24% spinal/epidural anaesthetic. The most common symptoms reported were pain 100% (most commonly neurogenic with dysesthetic and lancinating pain), with numbness/tingling, sleep disturbance, weakness and muscle cramps reported by more than 80% of respondents1.

More recently, data from a case series of 162 arachnoiditis patients in the US (Aldrete 2000) described the prevalence of a large range of symptoms including back and leg pain, where 93% of patients experienced severe chronic back pain. Other symptoms such as sleep disturbances, low grade fever, headaches, bladder, bowel, sexual dysfunction and muscle spasms were evident. Also, the majority of cases were not working, required assisted care, had frequent doctor visits and were taking pain medications but still experienced pain. The reliance upon daily narcotic analgesics is high in reported case series.

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 atypical and present a complex clinical picture.

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1 www.aboutarachnoiditis.org/content/1999_arachnoiditis_survey

ARACHNOIDITIS: A BRIEF SUMMARY OF THE LITERATURE
Underlying diseases such as meningitis, recent herniated disc, spinal stenosis, facet arthropathy may all overlap with arachnoiditis (Aldrete 2000). A recent review concluded that arachnoiditis is a clearly defined radiological entity and clearly defined pathological entity, but is not a clearly defined clinical entity. The pathological and radiological changes of arachnoiditis may be present in the absence of symptoms. “The causative relationship between radiological changes of arachnoiditis and clinical changes has not been sufficiently demonstrated”. If symptoms and radiological changes are present in studies, “a causal relationship is implied but not explicitly stated” (Petty et al. 2000).

Newer imaging techniques such as MRI of the lumbar spine have allowed for more and smaller abnormalities to be detected, but the relationship between these abnormalities and low back pain are controversial. Various studies have reported the high percentage of individuals never having back pain or sciatica showing abnormal myelograms (24%), computerised tomography scans (36%) and MRI (30%) (Boden et al. 1990). In one study, the MRI examination of 98 asymptomatic people found that many without back pain have disk bulges or protrusions, but not extrusions. Such findings in people with lower back pain may be coincidental (Jensen et al. 1994), and any operative treatment must be carefully correlated with age, clinical signs and symptoms (Boden et al., 1996). Dependence on MRI alone, without discography, could lead to “significant error both in over-treatment of clinically asymptomatic desiccated discs and under-treatment of clinically significant pathology” (Simmons et al. 1991). The high prevalence of back pain coupled with uncertainty over the cause and the sometimes loose association between symptoms, anatomical findings, and imaging results has contributed to the larger number of fads in treating this condition (Deyo 1994).

Several studies have reported that residual contrast dye Iophendylate in the spinal sub-arachnoid space may closely resemble spinal canal tumours on MR imaging of the spine (Anand et al. 1987) or MR signal characteristics similar to fat (Hackney et al. 1986), and that these need to be clearly differentiated.

**Summary**

Radiology has provided objective evidence of arachnoiditis. The development of radiological diagnostic technologies have allowed for greater anatomical detail of the spinal meninges and surrounding structures to become available. MRI has become the diagnostic test of choice with its non-invasiveness and the greater degree of anatomical detail it provides. But the relationship between abnormalities and low back pain is controversial as asymptomatic patients have been shown to have abnormalities. The literature contains varied descriptions of the “clinical syndrome” of arachnoiditis. There is no “typical” clinical pattern in patients. Arachnoiditis presents as a complex clinical picture given the varied origin, type, location and distribution of symptoms. Chronic severe back and/or lower leg pain is the most common presenting symptom. The clinical history of most patients includes presentation for back injury and back/leg pain and prior multiple myelograms and back surgeries. Some patients may not improve and are diagnosed with a class of “failed back” syndromes. Arachnoiditis is not well described in medical text books, disease classification and diagnostic taxonomy systems. Other existing spinal pathologies may also overlap with arachnoiditis. The exact relationship between the radiological and pathological entities of arachnoiditis and the clinical syndrome remains to be clearly demonstrated.

**ESTIMATES OF THE PREVALENCE AND INCIDENCE OF ARACHNOIDITIS**

If a comprehensive epidemiological study was undertaken, it would be revealed that arachnoiditis in all its forms would be more common in its incidence (new cases of arachnoiditis over a period of time), and prevalence (the proportion of the population who have arachnoiditis at a specific point in time). This is because inflammation is a normal response to surgery, trauma and infection in the sub-arachnoid space, and arachnoid adhesions are a common entity but typically of no clinical significance (Burton 1997). All degrees of inflammation could be termed arachnoiditis but the term associated with estimates of incidence and prevalence appears to be reserved for more clinically obvious forms, usually chronic adhesive arachnoiditis.
There are no data on the actual population-based prevalence and incidence of arachnoiditis in any country, in any of its forms. Published estimates are based upon adverse events arising from various procedures. Estimates are varied and anecdotal but generally indicate that chronic adhesive arachnoiditis is rare. No clear consensus on estimates is evident largely because of varied diagnoses of arachnoiditis and inadequate methodology used to calculate these. Current estimates cannot be generalisable to the general population given the case sample sizes and diversity. There are also immense difficulties in defining the population at risk given the multiple etiological factors attributed to arachnoiditis. See also New Zealand incidence and prevalence (see Appendix 2).

The following examples were identified to illustrate the variation in estimates. Incidence estimates based on multiple case series have been made ranging from one case per 10,000 to one case per 25,000 (Adriani and Naragi 1986). The prevalence of post-operative arachnoiditis diagnosed by MRI independently of the use of a myelographic contrast agent was estimated to be 4.6%, six cases in 129 cases examined. The causes and clinical significance of these are speculative (Fitt and Stevens 1995).

Long (1992), estimated the more progressive forms occurred in less than 10% of patients studied with apparent arachnoiditis but no more than half of these appeared to be symptomatic because of arachnoiditis alone. Estimates from cases reported in the literature over 50 years up to the early 1990’s, indicate the number of cases reported to be no more than 1,000 patients. However, not all existing cases were identified in Long’s review or reported in medical literature given that the entity has been known since at least 1909 or earlier (Aldrete 2000).

The 1999 Arachnoiditis Survey was a global postal survey of sufferers with a diagnosis of arachnoiditis including participants from New Zealand. Data was obtained from 317 respondents, 70% of whom were female and 88% aged 50 years or more. This survey provides only anecdotal self-reported data and there are interpretation difficulties with the wide range of symptoms and risk factors reported.

Few data were available on the incidence of arachnoiditis as a complication of infection, myelography, blood in the intrathecal space, anaesthetic substances in the spine, spinal surgical interventions, steroids and trauma. Incidence estimates were varied and were generally estimated from the numbers of procedures or were studies documenting the incidence of iatrogenic events and/or complications non-specific to the syndrome. The problem often with these incidence estimates of arachnoiditis were that multiple confounding factors were not accounted for in the calculations – i.e., many patients who have undergone myelograms have also had other confounding events such as back surgery. These estimates of the incidence of clinically significant arachnoiditis can only be considered as crude estimates. The following examples from the literature reviewed provide examples of incidence estimates derived in this way.

Estimates were made of an incidence rate of approximately 1% for clinically significant arachnoiditis based on a review of 80 cases diagnosed from 7,600 contrast investigations (Shaw et al. 1978). These cases were attributable to Myodil or Pantopaque myelography, back surgery and a previous spinal condition, most commonly lumbar disc disease.

A review (Nelson 1993), of the literature on intrathecal and epidural steroid methylprednisolone acetate (MPA) therapy states that studies have identified errors in the placement of epidural needles and resultant inadvertent dural or arachnoid punctures ranging from 0.5% - 2.5% (Albright 1978), to 5% - 6% (Abram 1989); depending on experience and the disease being treated (Dilke et al. 1973), and injections into interspinous ligaments, 25% (Nelson 1989). Nelson estimated that if one assumes a maximum of 6% inadvertent spinal taps from epidurals and that 20% of patients following intrathecal injections develop clinical arachnoiditis, then the theoretical complication incidence rate is 1.2%. This figure is much higher than complications reported, however, his method relies only on a single follow-up case study where 20% (3 of 15) developed these complications (Johnson et al. 1991).

A review (Abram and O’connor 1996), of complications associated with epidural steroid injections for sciatica found no reports of clinically significant arachnoiditis in patients who had received one or more epidural steroid injections. Some 71 case series studies included 7,189 patients while another 24 studies with 3,040 reported patients did not address the issue of complications. Several cases of
arachnoiditis were reported after repeated sub-arachnoid steroid injections over a long time period in studies involving 521 reported patients.

Estimates of the annual number of surgeries for lumbar disc disease performed in the US range from 200,000-400,000. The failure rate of surgery over the past 50 years has been estimated to be 25%, but is more typically 10% today due to advances in diagnosis, treatment and surgical expertise (Burton 1997). These patients could be classified as having Failed Back Surgery Syndrome (FBSS). A study on the etiology of failed lumbar spinal surgery by institutions involved in rehabilitation estimated 11% of these cases to be directly caused by adhesive arachnoiditis with primary cause exposure to the contrast agent iophendylate. This combined with an incidence rate of 1.2% derived from a retrospective study of autopsies resulted in approximately 320,000 US cases of clinically significant arachnoiditis over the past 50 years (Burton 1996). No country has reliable statistics to verify these estimates.

On general complications resulting from injection therapy, recent literature includes a Swedish study which reports incidence rates of neurological complications after anaesthesia of one case per 2,834 spinal blocks and possibly up to one case of “irreversible damage” per 923 epidural blocks, although this association is complex in some cases (Dahlgren and Tornebrandt 1995). Another Finish study reports serious complication incidence rates of 0.45 per 10,000 for spinal and 0.52 per 10,000 for epidural blocks (Aromaa et al. 1997).

A French study of complications of obstetrical epidural analgesia quantified maternal complications from 300,000 epidurals over five years. The overall serious complication incidence rate was one in 4,005 epidurals, dural puncture one in 156 being most common, massive sub-arachnoid injections one in 8,010 and convulsions 1 in 9,011 (Palot et al. 1994).

Summary

Incidence and prevalence estimates of clinically significant arachnoiditis are problematic. It is not possible to calculate the actual population-based incidence or prevalence of arachnoiditis in any form. The necessary clinical data are not available to accurately estimate arachnoiditis in any form. The estimates that appear in the literature refer to clinically significant arachnoiditis and are based on case series, procedures linked to an etiological contributor or iatrogenic events data. The literature that is available tends to indicate that clinically significant arachnoiditis is rare. These estimates are anecdotal, varied and are not generalisable to the population as the population at risk is 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. The most likely factors in reducing potential incidence are advances in new radiological and surgical techniques reducing the risk of etiological events linked to arachnoiditis. The true ascertainment of arachnoiditis cases requires the capture of clearly diagnosed cases, perhaps through mandatory disease notification and definition of the population at risk. Given the immense costs involved, the difficulties in clinical diagnosis and the relative rarity of the condition such an undertaking is unlikely. The total reliance on clinical experience combined with the rareness of the condition would seem to preclude it from demographic study.

PROGNOSIS AND TREATMENTS

Prognosis

There is little literature on the prognosis of arachnoiditis with few studies looking specifically at prognosis over the long-term. There are complexities in answering questions on the prognosis of arachnoiditis in patients because of the difficulties in clinical diagnosis and treatment of this painful and disabling condition which is often complicated by the ageing process and pre-existing spinal pathologies. In the few articles available reported prognosis is poor in most cases; it is “not good at best, and is dismal at worst” (Aldrete 2000).

The only study identified with long-term follow-up of 10-21 years in 36 patients in the US showed that though symptoms fluctuated, pain and function did not deteriorate. There was no evidence of
progression or of improvement either (Guyer et al. 1989). No specific clinical syndrome was identified but back and leg pain were typical and no obvious treatment was useful. Many patients relied on daily narcotic analgesics, and though not directly related to arachnoiditis the average life span was shortened by 12 years. Progression of symptoms and functional impairment were not indicative of the natural course of the disease.

Shaw et. al. (1980), emphasised the changing nature of spinal arachnoiditis. In the early part of last century the disease complicated infection and trauma and was highly progressive to paraplegia. In their study group of 80 patients diagnosed with arachnoiditis, apparently as a complication of multiple and poorly done myelograms and back surgeries, the patients did not have the same relentless progression as earlier forms of arachnoiditis.

Other studies have retrospectively analysed case histories in an attempt to illustrate the progression of the disease. The variability in prior myelograms and back surgeries, in time-lapse before symptom onset and the distribution and type of these symptoms is evident (Bourne 1990), (Mooij 1980). The conclusion that these and others have reached is that there is no cure for the condition, only degrees of palliative care of the symptoms.

Case studies of rare forms of arachnoiditis, such as arachnoiditis ossificans, have also appeared in the literature describing the progressive nature of the ossification process and the deterioration in the patient (Mello et al. 2001).

Summary
There is a significant lack of literature dealing with the prognosis of arachnoiditis. What studies there are tend to indicate that 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.

Treatments
Arachnoiditis is a complex neurogenic pain condition. Much of the literature on treatment other than specific surgical treatment is related to chronic non-cancer pain management and more specifically low back pain and failed back and post-laminectomy syndromes. These study populations are non-specific to arachnoiditis and include a wide variety of diagnoses. The little specific literature on the treatment of arachnoiditis is clinically anecdotal and deals with the case series of the clinician in treating patients. It is apparent from these that effective treatments are difficult to achieve. The book by Dr Aldrete, a pain management physician, has been particularly useful on providing information about analgesics commonly used in treating arachnoiditis patients in the brief summary on medical treatments (Aldrete, 2000).

Most cases of chronic adhesive arachnoiditis are complex and multi focal and it is difficult to link intractable pain to the condition, the exact relationship between anatomical arachnoiditis and pain has not been clearly documented. The pain mechanism is thought to result from the encasement of the preganglionic spinal nerves in collagenous scar tissue and an increase in intraneural tension coupled with restriction in axoplasmic flow, neurohumoral transport, arterial supply and venous return (Burton 1996). Pathological evidence indicates that progressive atrophy is the resulting nerve response to such trauma. The nociception (pain sense) of continuous pain receptor electrical discharge is thought to be related to these compromised nerve roots.

Therapy for arachnoiditis is palliative; it tends to relieve some symptoms, provide pain relief and give assistance with functional impairment but in most cases does not cure. Therapy is “generally unsatisfactory and symptomatic at best” (Long 1992). A regimen of medicine, physiotherapy, exercise and psychotherapy is recommended, providing a multidisciplinary approach to pain management in arachnoiditis sufferers (Aldrete 2000).
Medical treatment

A range of adjuvant medications have been useful in treating patients with arachnoiditis. As well as treating depression, insomnia and anxiety, antidepressants have been widely used in the treatment of neuropathic pain but the precise mechanism of how these affect pain pathways is not clear. Most antidepressants act through replenishing monoamine neurotransmitters such as serotonin through uptake inhibition in areas of the brain that regulate well-being. Higher than normal doses of antidepressants (venlafaxine) with significant norepinephrine uptake activity reduced pain in most arachnoiditis patients (Aldrete 2000).

Non-steroidal anti-inflammatory drugs (NSAID) have less pain relieving effect than analgesics but have anti-inflammatory properties. Newer compounds (cyclooxygenase II inhibitors) with fewer side effects have been useful in the early inflammatory stage of arachnoiditis with minimal differences between various types of NSAID on equivalent doses (Aldrete 2000).

Anticonvulsants, particularly the newer drug gabapentin, have been shown to be effective in pain and muscle spasm relief in patients with peripherally mediated neuropathic pain (Merren 1998). A cross-over study comparing phenytoin with gabapentin in the treatment of arachnoiditis patients over six months showed both significantly reduced most symptoms, though greater side-effects were experienced with the latter drug (Aldrete et al. 2000). Muscle relaxants such as baclofen, used to suppress motor spasticity in patients with spinal cord injuries, have been effective as an adjuvant analgesic therapy. Magnesium also has suggested benefit.

Opiates have been used to ameliorate the complex phenomenon of symptoms where neuropathic pain predominates. There is debate over the use of opiates in chronic non-malignant pain patients. The issues include the concern over long-term opium-derivative use and developing drug dependency, side-effects, the therapeutic benefit of controlled-release opiates, and the use of methadone, slow-release morphine and oxycodone. Given the inadequacy of controls, patient follow-up and small number of patient series in studies the investigation and debate over these issues continues (Aldrete 2000). Some arachnoiditis patients have benefited with pain relief from opiates but unresolved issues remain for long-term non-cancer-related pain opiate treatment.

Other alternative therapies have been used in pain management including massage, yoga, osteopathic medicine, physiotherapy, relaxation, hypnosis, biofeedback and nutritional supplementation. Often the best sources for advice on such therapies are the growing number of patient support groups worldwide.

Summary

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. From the little specific literature 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 in patients. The use of narcotics for chronic non-cancer pain treatment while providing pain relief remains controversial. A wide regimen of therapeutic treatments appears to be a useful approach.

Interventional pain relief procedures

There is an extensive body of literature concerning the use of epidural steroid injections for a range of etiologies. But much of it is descriptive and anecdotal and there are few controlled trials on the efficacy of such treatments. These trials are limited by methodology and technique (Cannon and Aprill 2000). Data on the efficacy of steroids administered via the epidural route is limited and although they may be effective in treating lower back pain their role in therapy still remains to be adequately determined (Tonkovich-Quaranta and Winkler 2000). A Cochrane systematic review of 21 clinical controlled trials of injection therapy for subacute and chronic benign back pain concluded that such therapy had not been shown to be effective or ineffective (Nelemans et al. 2001). There was a tendency towards non-significant positive results and minor side-effects but there was no justification to abandon such therapy. With a lack of significant results and well designed trials, solid evidence is lacking.
Nerve root compression and inflammation are thought to be factors contributing to back pain and sciatica. The administration of corticosteroids are thought to reduce inflammation and provide some analgesic benefit especially if administered directly to an area via the epidural or intrathecal route. Other modalities including temporary or permanent epidural and intrathecal infusions have been used in an attempt to prolong pain relief from transient single shot injections. A wide range of patients with varying diagnoses have benefited from injection therapy including arachnoiditis patients. The benefits of pain relief have been reported in a significant number of arachnoiditis patients treated with Depo-Medrol through intrathecal injection (Wilkinson 1992). He also concluded that there is little evidence that Depo-Medrol used in moderation is harmful. There are few reports on serious complications resulting from preservatives in steroid formulations used for injection therapy. Most of those reported followed multiple and/or poorly performed injections. This remains controversial and the role of these remains to be determined (Tonkovich-Quaranta and Winkler 2000). It is generally recognised in anaesthetic practice that substances containing preservatives (benzyl alcohol, methylparabens, propylparabens) should not be administered epidurally or intrathecally because of the reported risk of anaphylaxis and neurotoxicity (Hetherington and Dooley 2000). Although intrathecal administration into the sub-arachnoid space is important in the management of symptoms this route of administration can increase the risk of local adverse effects such as arachnoiditis.

Longer lasting pain-free lapses in arachnoiditis patients have been reported with epidural and intrathecal infusions using pumps. Temporary epidural infusions using disposable infusion pumps are said to offer “reasonable, safe and worthwhile” therapy (Aldrete 2000). Although benefiting patients where other conservative therapy has failed, the risk of complications arising particularly from permanent pump infusion modalities are also apparent.

Summary

There is no one optimal analgesic method that is permanent. Even short-term pain relief can be seen to warrant continued use despite the often high cost, warnings and hazards of such treatments (Aldrete 2000). Although there is an abundance of literature, better designed clinical trials on the efficacy and safety of steroid injections and infusions are needed to better determine their therapeutic role.

Electrical stimulation of the nervous system

Advances in technology have meant spinal cord stimulation devices have become safer and less invasive. Originally spinal cord stimulation used monopolar electrodes surgically implanted into the dura mater. This technology has developed into percutaneous multi-channel electrode arrays and a controller implanted into the epidural space. The controller allows for the alteration of pulse width, duration and intensity of electrical impulses. This newer technology uses needle probes in the soft tissue and/or muscles in the pain location to stimulate peripheral sensory nerves. The patients included in the series in the published literature on electrical stimulation of the nervous system represent a variety of diagnoses including those with syndromes and diagnoses associated with arachnoiditis. An evidence-based review of the literature on spinal cord stimulation for chronic pain found that there was insufficient evidence on the efficacy of such treatments in people with “failed back syndrome” (Stocks and Williams 2001).

Evaluation is needed with well designed controlled trials. There are few studies where a specific diagnosis of arachnoiditis is specified. For example a group of patients for whom conventional pain management had failed included some patients with pain secondary to arachnoiditis or perineural fibrosis confined to one nerve root level. These patients responded favourably to treatment by epidural stimulation (Kumar et al. 1991). A similar finding was made with patients with single nerve root injury or mononeuropathy compared to arachnoiditis patients with multiple injured nerve roots (Meilmann et al. 1989). These and other similar studies have indicated some benefit from electrical stimulation to cases with localised arachnoiditis. The use of spinal neurostimulators for the relief of intractable pain produced in arachnoiditis has been indicated particularly if patients are carefully selected and tested (Burton 1996). There are also reports of complications such as aseptic meningitis, bleeding, infection and equipment failure, and treatment resulting in little or no improvement (Aldrete 2000).
**Summary**

Although technological advances have made spinal cord stimulation devices safer and less invasive and there are indications of pain reduction in some arachnoiditis cases, there is remaining uncertainty over the benefits and long-term results of these treatments.

**Surgical treatment**

The pathological nature of intermediate to severe arachnoiditis with its scarring and fibrosis presents as a possible indication for surgical lysis of adhesions or removal of scar tissue. Arachnoiditis patients may also have other morbidities such as spinal stenosis or recurrent herniated disc which also could be indications for surgical procedure (Aldrete 2000).

Surgical intervention in patients with arachnoiditis is controversial given the potential benefits and hazards of such treatment. The results of surgical intervention from published studies generally reveal poor or only short-term relief in most cases. Surgical interventions have led to the alleviation of pain and symptoms through freeing the dura of adhesive neural tissue (spinal cord and nerve roots) and scar tissue, sometimes re-establishing cerebrospinal fluid dynamics and vascularity in some patients (Shikata et al. 1989), (Roca et al. 1993). Surgical intervention has also been linked to the exacerbation of existing arachnoiditis conditions (Johnston and Matheny 1978), (Fager and Freidberg 1980). Surgery has long been recognised as an etiological factor in the development or recurrence of arachnoiditis (Quiles et al. 1978). In some patients an exaggerated inflammatory reaction of the arachnoid membrane occurs which can develop into adhesion, scarring and even ossification processes (Auld 1978). It is thought that the incidence of lumbar spine surgery failure has declined due to better practices, conservative management, and advances in diagnostic technology (Burton 1991).

Surgical intervention is extremely challenging often involving the dissection of individual nerves from dense scar tissue under magnification where potentially nerve roots can be easily damaged. Newer technologies such as percutaneous intrathecal endoscopy, lysis of adhesions or the application of local scar-prevention substances and dural substitutes may reduce complications but await further evaluation (Aldrete 2000).

Based on his clinical experience, Long (1992), reported that he reserved microlysis operations for a small number of arachnoiditis patients with either progressive neurological deficits, incapacity or failure of other treatments to address intractable pain. Some 35 patients who had operations were evaluated over 20 years. The success rate was initially around 50% but this reduced with time. Most patients with arachnoiditis were not candidates for direct surgical intervention.

There has been a tendency to label or group many lumbosacral pain disorders into low back pain. Patients with recurring pain following back surgery have similarly been labelled as having post-laminectomy syndrome and in those with recurrent pain after repeated operations the labels failed fusion pain or failed back syndromes have been used. Patients could have any of a range of disorders such as spinal stenosis, bulging disc, dural and nerve root injuries, cauda equina syndrome, scar tissue formation and arachnoiditis (Carroll and Wiesel 1992). The origin of the problem can often be traced back to the original operative procedure. A standardised treatment is not suitable given the diversity of pathologies, symptoms, type and locations of pain. It is not surprising that surgical treatments have had such variable outcomes given the vast clinical spectrum. It is expected that a worse prognosis will result from lumbosacral surgery in patients who have complications such as spondylosis, radiculopathy, epidural scarring and arachnoiditis (Aldrete 2000).

Cochrane systematic reviews of randomised controlled trials have investigated surgical interventions for disc prolapse (Gibson et al. 2001a) and degenerative lumbar spondylosis (Gibson et al. 2001b). The patient populations included in these reviews are broad as they are inclusive of a range of surgical procedures on patients of any age with signs and symptoms of lumbar disc prolapse or with degenerative lumbar spondylosis. Adhesive arachnoiditis was identified in the outcome measures under adverse complications for the study inclusion criteria but this was not specifically evaluated as an outcome. The review of 27 RCT’s on surgery for disc prolapse concluded that most lumbar disc prolapses given time and conservative management resolve naturally. Where surgery is indicated, discectomy is effective in carefully selected patients with sciatica due to lumbar disc prolapse although
the long-term outcomes are unclear and chemonucleolysis (dissolution of the nucleus by injection) is comparatively less effective but is less invasive (Gibson et al. 2001a). The review of 16 RCT’s on degenerative lumbar spondylosis surgery concluded that there is a lack of evidence regarding the efficacy of any surgical decompression or fusion compared with placebo, conservative treatment or natural history (Gibson et al. 2001b).

**Summary**

Although the pathological nature of arachnoiditis presents as a possible indication for surgical intervention, this is mostly reserved for carefully selected patients with consideration for the patients who have underlying spinal pathologies. Surgical intervention in patients with arachnoiditis remains controversial given 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.

Patients often have a range of disorders including arachnoiditis. Standardised surgical treatment is not justifiable given the diversity of pathologies, symptoms, type and locations of pain. The vast clinical spectrum of underlying disorders explains why surgical treatments have had such variable outcomes.

**FUTURE PERSPECTIVES AND PREVENTION**

**Future perspectives**

The broad and clinically anecdotal nature of the medical literature on arachnoiditis and lack of systematic and coordinated research has meant that arachnoiditis has remained in relative scientific isolation. From the literature reviewed for this report it is apparent that the condition is generally considered to be rare which may be an underlying reason why greater coordinated research efforts have not eventuated. There is a lack of studies providing sufficient evidence on aspects related to the etiology, pathology, diagnosis and treatment of the condition. It is probable that the controversies identified from the literature and the lack of definitive treatments are likely to continue unless efforts are made to address these. Continuing debate may provide a catalyst for future research into arachnoiditis.

There has been a push for greater recognition of arachnoiditis as a public health issue by patient support groups and a small group of clinical specialists. Their continuing role is to educate the medical profession and public about the condition and the possible effects of invasive procedures, promote epidemiological study and to ascertain the prevalence and incidence of the condition. They will also continue to promote a collaborative research and treatment approach amongst neurologists, neurosurgeons, orthopaedic surgeons, radiologists, immunologists, pain management specialists, physiotherapists and sufferers.

The development of new treatments for neuropathic pain applicable to patients suffering from arachnoiditis could provide greater analgesic benefit than existing treatments. New promising drug delivery modes being researched include transdermal and intranasal delivery routes, slow release implantable lipid bags, and chronotherapy with the optimisation of pharmacological effects in patients’ biological rhythms (Aldrete 2000). Research is also being done in nerve recovery, muscle and endothelial cell repair. New diagnostic imaging technology has allowed for greater precision-guided surgery. Neural implants in the brain and spinal cord may be able to provide restoration of neural tissue and function.

**Summary**

It is unclear how coordinated and systematic research into arachnoiditis will proceed 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. These research efforts are needed as current diagnosis of clinical
arachnoiditis can equate to “a diagnosis of despair or a justification for otherwise unsustainable litigation” (Petty et al. 2000).

**Prevention**

The etiology of arachnoiditis established in the literature has not been without controversy but the changing nature of the debate during the last century has been recognised (Shaw et al. 1978). With the availability of antibiotic therapy, infectious etiology has been replaced by a range of factors considered to be of iatrogenic origin.

Many patients presenting for back surgery do so having had non-invasive CT or MRI without myelography. Thus the etiology of arachnoiditis in the future is likely to be related to post-surgical complications as myelograms gradually disappear. Other underlying conditions such as degenerative disc disease, disc herniation and spinal stenosis, which have been associated with arachnoiditis, also present as indications for surgical intervention.

Given this, an important focus of future prevention should be on the operative prevention of post-surgical complications. For example, a range of surgical principles outlined in Dr Aldrete’s extensive work include principles such as scar prevention, washout of synthetic material, gentle neural tissue handling etc (Aldrete 2000). These and other clinical guidelines provide important material on prevention that help to minimise the risk of post-operative complications. Other factors include careful patient selection and the use of newer non-invasive diagnostic technology. Also the use of conservative therapy and multidisciplinary approaches to treatments for failed back syndrome and low back pain have been recognised in the literature (Anderson and Israel 2000), (Frank and De Souza 2001).

Complications resulting from intrathecal steroid injection therapy for lower back pain and a range of radicular syndromes including arachnoiditis have been reported in the literature, though further research is needed. These reports appear to be linked to poorly placed and multiple injections over a long period of time with neurotoxic solutions containing high levels of preservatives. The risks of injection therapy complications could be reduced through greater care taken in the selection of steroid medication, the interval between treatments, the route of administration, delivery technique and dilution of steroid solution to prevent the concentration effects of preservatives.

**Summary**

Given the recognised iatrogenic etiology of arachnoiditis today, prevention will be an important part of any health strategy to address the 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 on evidence-based clinical guidelines and conservative and multidisciplinary therapy.
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 chronic 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.
Appendix 1

PRINCIPAL SOURCES OF INFORMATION

Bibliographic databases
- Medline
- Embase
- Current Contents
- Premedline
- Web of Science (Science/Social Science Citation Index)
- Index New Zealand
- Cochrane Controlled Trials Register

Review databases
- Cochrane Database of Systematic Reviews
- Centre for Reviews & Dissemination databases at University of York
- Database of Abstracts of Reviews of Effectiveness (DARE)
- NHS Economic Evaluation database
- HTA database
- Best Evidence (ACP Journal Club/Evidence-based Medicine)

Websites
- New Zealand Ministry of Health
- New Zealand Accident Compensation Corporation
- New Zealand Health Information Service
- Australian National Health and Medical Research Council
- National Institute of Neurological Disorders and Stroke
- The National Organization for Rare Disorders
- Chemically Induced Adhesive Arachnoiditis Sufferers of Australia
- New Zealand Arachnoiditis Sufferers Action and Monitoring Society
- The Arachnoiditis Foundation Inc
- The Arachnoiditis Trust
- The Arachnoiditis Support Group-Circle of Friends with Arachnoiditis
- The Burton Report
- The American Chronic Pain Association
- Current Controlled Trials
- Clinicaltrials.gov

Other
- The New Zealand Bibliographic database – Te Puna
- References cited in retrieved articles, both review and original articles
- Information supplied by the New Zealand Ministry of Health, New Zealand Health Information Service, the Accident Compensation Commission and the Arachnoiditis Sufferers Action and Monitoring Society.
SEARCH STRATEGIES

**Medline, Emerge, Premedline**
arachnoiditis/ (1406)
limit 1 to yr=1990-2001 (484)
arachnoiditis.mp. (1793)
limit 3 to yr=1990-2001 (686)
2 or 4 (686)
limit 5 to english (532)
remove duplicates from 6 (348)

**Other sources**
All remaining sources in which subject headings were not available were searched using the word *arachnoiditis* as a free text keyword.
Appendix 2

SUMMARY OF NEW ZEALAND EVIDENCE MATERIAL

The literature search located a very small number of New Zealand references on the National Bibliographic Database. The largest of these were nine booklets published and available by Internet from the Arachnoiditis Sufferers Action and Monitoring Society (ASAMS), covering topics such as adhesive arachnoiditis syndrome, arachnoiditis: red blood cell shape analysis and implications for treatment, chronic headache, chronic pain, epidural anaesthesia and arachnoiditis, sciatica and disc prolapse: a patient’s guide. An MA thesis was also found on the presenting symptoms associated with arachnoiditis and the experience of living with them in everyday life.

ARACHNOIDITIS AS A PUBLIC HEALTH CONCERN IN NEW ZEALAND

The emergence of arachnoiditis as a public health concern in New Zealand, from material provided by the Ministry of Health, is outlined below:

A number of newspaper articles and TV programmes appeared in the 1990’s concerning alleged complications particularly arachnoiditis from Myodil (a contrast agent containing iophendylate used in spinal x-ray) and Depro-Medrol (epidural/intrathecal injected steroid used in back pain management). There was widespread media and public interest at the time.

Myodil oil-based x-ray contrast dye was withdrawn from the New Zealand market by Glaxo in 1987 due to decreased sales, and not at the request of the Ministry of Health on safety grounds. It was replaced by safer ionic (later non-ionic) water-based radiographic agents, which in turn have given way to newer CT scan and MRI technology. During the 1960’s and 1970’s, Myodil was the only available spinal diagnostic contrast agent and was available in New Zealand prior to legislation controlling medicines introduced in 1962. The Glaxo Myodil pack insert (November 1973 edition), lists post-myelography arachnoiditis under adverse reactions but this is qualified by statements about a lack of clear literature evidence to confirm this. Up until 1995, the Adverse Reactions Committee had no official record of any significant complaints related to the use of Myodil. The Ministry position at this time was that arachnoiditis, as a rare side effect of iophendylate, was based on little evidence in the literature.

The safety and efficacy of the epidural steroid Depro-Medrol containing methylprednisolone for the management of back pain was reviewed by the Medicines Adverse Reactions Committee (MARC) in 1991 and late 1996. The conclusions of the latter review were:

- there is inconclusive and insufficient evidence in the literature concerning the efficacy of such injections for back pain
- the underlying aetiology of conditions in recipients of these epidural steroid injections is unclear. Some literature states that it is impossible to determine whether arachnoiditis is secondary to the original injury or radiological, surgical or medical (epidural injection) intervention. It was also noted that some studies had failed to link the radiological evidence of severity of arachnoiditis to the severity of symptoms
- further research is needed to determine the safety and efficacy of epidural steroid injections. In the interim, practice should continue only on the basis of explicit informed patient consent.
The New Zealand Pain Society was advised of the conclusions and asked to prepare patient information leaflets with consent forms. Medical practitioners were advised on the use of epidural steroid injections and responsibility to the patient in a 1998 issue of the Ministry’s publication *Prescriber Update*. Neither the route of administration nor indication are approved in New Zealand. The manufacturer, Upjohn, included an underlined warning that epidural use was not recognised as an indicator for Depo-Medrol. The 1991 package insert states that epidural use was not recommended. There are provisions in the Medicines Act 1981 for the administration by a non-approved route and for an unapproved indication. The code of Health and Disability Services Consumer Rights places responsibility on the prescribing or administering medical practitioner to advise recipients of expected risks, side effects and benefits (Right 6(1)(b)). Written consent was also required in experimental treatments (Right 7(6)(b)) which could possibly apply in the case of epidural Depo-Medrol injections.

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Patient safety and informed consent issues have appeared more recently in New Zealand medical literature. The incoming NZMA President, Roy Holmes, raised the patient safety issue in New Zealand, citing findings from an Australian study of quality healthcare in NSW for NSW where some 16.6% of admissions were associated with an adverse event, over half judged to have high preventability (Holmes 2000).

Patient safety issues have also made recent news with the results of an Auckland region adverse events feasibility study (Davis et al. 2001). This showed that medical adverse events were more likely to have occurred outside hospital, to be drug related, to be associated with acute admission, to be classified as highly preventable and to have greater impact on hospital stay. Post-lumbar puncture headache was a common procedure-related adverse event. This can occur following either spinal or epidural anaesthesia but also following diagnostic procedures such as myelograms. This is caused by leakage of cerebrospinal fluid into the epidural space and correlates strongly with needle-diameter size and needle direction and angle. The development of clots after bleeding has been implicated with arachnoiditis but given the widespread use of epidural blood patches for post-lumbar headache this is unlikely (Parnass and Schmidt, 1990). The formation of post-lumbar puncture dermoid and epidermoid intradural cysts has been clearly documented but has not been conclusively shown for intradural arachnoid spinal cysts (Kriss and Kriss 1997).

Coates and Hill (2001), outline the criteria for obtaining informed consent from women in labour undergoing epidural analgesia. Three basic criteria for patient consent must be satisfied, patient competency or legal capacity, adequate patient information (available options, risks and side effects) and voluntary consent (free from duress). Ideally, patient consent should be obtained in writing by the anaesthetist after consultation with the patient. This is not legally essential unless a patient is to go under general anaesthetic, there is significant risk of adverse events, there is participation in research, or a procedure is experimental. Patient competency due to impairment from pain, fatigue, confusion etc still gives the right to make informed choice to the extent appropriate to the level of competence (Coates and Hill 2001). Some debate over what constitutes an acceptable level of risk as it relates to informed patient consent have also appeared and concerns with low risk but the potential for life long afflictions.

Various New Zealand support groups within the National Neurological Organisations Network and disability support networks exist. The central arachnoiditis support group in New Zealand is the Arachnoiditis Sufferers, Action and Monitoring Society (ASAMS). This was established in 1995 following a TV program about arachnoiditis called *A Shot in the Back*, and subsequent newspaper articles. Some 650 inquiries were received by the Wanganui Disability Resources Centre at the time. The ASAMS provides support for sufferers and caregivers, information on the condition and the possible dangers of medical procedures linked to arachnoiditis, education of medical professionals about proper patient informed consent and help to set up similar support groups around New Zealand. Their web site, which includes extensive resources is at www.aboutarachnoiditis.org.

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Summary

Arachnoiditis has emerged as a public health concern in New Zealand owing to the formation of patient self-help groups here similar to those in the United States, England and Australia. These organisations have lobbied the medical profession and governmental health organisations over what they see as a high global incidence of arachnoiditis secondary to myelography and injection therapy and promoted the recognition of arachnoiditis as a disease entity. In New Zealand this lobbying led the Ministry of Health to investigate patient support group concerns. The reviews were inconclusive owing to insufficient evidence being available. Recent patient safety and informed consent issues raised in the literature have placed responsibility on the prescribing or administering medical practitioner to advise recipients on expected risks, side effects and benefits of treatments. A current review is broader than those previously carried out and brings together recent literature and available New Zealand data for the first time.

NEW ZEALAND PREVALENCE AND INCIDENCE DATA

There is no reliable New Zealand data on the incidence or prevalence of arachnoiditis. The New Zealand Health Information Service (NZHIS) has some incomplete data. Public hospital inpatient data is based on ICD-9/10; this allows for coding for arachnoiditis under inflammatory diseases of the central nervous system. This is coded under meningitis of other unspecified cause (ICD-9 code 322) under meningitis, unspecified (ICD-9 code 322.9). ICD-10 is more specific with meningitis, unspecified (arachnoiditis (spinal) NOS) included in here. According to NZHIS coding staff, arachnoiditis could also be coded but not identified as 320 (bacterial meningitis), 036 (meningococcal infection), 013.0 (tuberculous meningitis) or 094.2 (syphilitic meningitis). Other non-specific codes could possibly include this condition – e.g., 724.4 (lumbosacral neuritis or radiculitis), unspecified or 952.2 (lumbar cord injury without evidence of spinal bone injury) but there is no way of knowing the extent to which this has been used. This is coded as ICD-9 322 (meningitis of other unspecified cause) and code 322.9 (meningitis, unspecified). Free-text fields for clinical coding provide some additional information for the 322.9 code (Table 1).

Table 1. Number of unique patient discharges from public hospitals under ICD-9 codes 322.9, 036.0, 094.2 and 013.0, for 1992 to 2000

<table>
<thead>
<tr>
<th>Year</th>
<th>Number with “arch” in free-text description</th>
<th>Total number with 322.9 code</th>
<th>Total number all codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>13</td>
<td>112</td>
<td>208</td>
</tr>
<tr>
<td>1993</td>
<td>14</td>
<td>103</td>
<td>244</td>
</tr>
<tr>
<td>1994</td>
<td>11</td>
<td>103</td>
<td>238</td>
</tr>
<tr>
<td>1995</td>
<td>7</td>
<td>120</td>
<td>344</td>
</tr>
<tr>
<td>1996</td>
<td>9</td>
<td>146</td>
<td>447</td>
</tr>
<tr>
<td>1997</td>
<td>8</td>
<td>165</td>
<td>500</td>
</tr>
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<td>1998</td>
<td>6</td>
<td>140</td>
<td>376</td>
</tr>
<tr>
<td>1999</td>
<td>4</td>
<td>153</td>
<td>423</td>
</tr>
<tr>
<td>2000</td>
<td>1</td>
<td>183</td>
<td>450</td>
</tr>
</tbody>
</table>

New Zealand Health Information Service

According to the NZHIS, arachnoiditis is largely unidentifiable as it is coded using meningitis codes, unless the coder has specifically changed the text description to “arachnoiditis” using additional available clinical information. The decrease in the number of specific cases is due largely to the increasing use of encoders that insert standard text descriptions for the code.
Given the varied nature of descriptions of arachnoiditis in the literature, clinician understanding and coding practice in this country, there is no way of ascertaining accurate incidence of this condition based on hospital inpatient data.

The 1996/97 New Zealand Health Survey and the 1996/97 New Zealand Disability Survey have no specific data on this.

The recent New Zealand Adverse Events study of 14 hospitals (Professor Peter Davis, Department of Public Health and General Practice, Christchurch School of Medicine and Health Sciences) was searched for useful information. However, the data collected from medical records is non-specific to arachnoiditis and limited retrospectively.

The ACC have paid out on a small number of claims (2) related to arachnoiditis. They were dealt with on a case by case basis and involved expert opinion. The main ACC database has no specific code for arachnoiditis, but the medical intervention database has assigned an event code to arachnoiditis given the number of claims (44) received. Data are stored under specialty (anesthesia, radiography), event (myelogram, radiculogram, Depo-Medrol epidural) and injury (arachnoiditis) code (Table 2).

### Table 2. Number of ACC arachnoiditis claimants, date of procedure, claim status and event type

<table>
<thead>
<tr>
<th>Year of Procedure</th>
<th>Number of claims*</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;=1992</td>
<td>35</td>
<td>81.4</td>
</tr>
<tr>
<td>1994</td>
<td>2</td>
<td>4.7</td>
</tr>
<tr>
<td>1995</td>
<td>1</td>
<td>2.3</td>
</tr>
<tr>
<td>1996</td>
<td>2</td>
<td>4.7</td>
</tr>
<tr>
<td>1997</td>
<td>2</td>
<td>4.7</td>
</tr>
<tr>
<td>1999</td>
<td>1</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>43</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

* Excludes one claim where the date is unclear

<table>
<thead>
<tr>
<th>Claim status</th>
<th>Number of claims</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepted</td>
<td>2</td>
<td>4.5</td>
</tr>
<tr>
<td>Withdrawn</td>
<td>6</td>
<td>13.6</td>
</tr>
<tr>
<td>Declined</td>
<td>32</td>
<td>72.7</td>
</tr>
<tr>
<td>Current</td>
<td>3</td>
<td>6.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Event code</th>
<th>Number of claims</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myelogram</td>
<td>39</td>
<td>88.6</td>
</tr>
<tr>
<td>Radiculogram</td>
<td>2</td>
<td>4.5</td>
</tr>
<tr>
<td>Depo Medrol epidural</td>
<td>3</td>
<td>6.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Source: MMFT/ACC 15/8/01

Most ACC claims have been rejected because the injury was related to the accepted procedure (myelogram) of the time (1960’s and 1970’ts), and expected complications were not unknown (ACC estimate 2%-5% poor outcome). The condition did however meet the severity criteria of 28+ days of incapacity. In the two successful claims (myelogram events), a high degree of severity impacted on the rarity (making it a rare event), so these claims were paid out.
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 (Table 3).

Table 3. ASAMS membership statistics and ethnicity as at May 1, 1999 and reported procedure prevalence as at July 2001

<table>
<thead>
<tr>
<th>Age group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>under 20</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>20 – 39</td>
<td>20</td>
<td>45</td>
<td>65</td>
</tr>
<tr>
<td>40 – 64</td>
<td>35</td>
<td>70</td>
<td>105</td>
</tr>
<tr>
<td>65 – 75</td>
<td>35</td>
<td>30</td>
<td>65</td>
</tr>
<tr>
<td>over 75</td>
<td>25</td>
<td>35</td>
<td>60</td>
</tr>
<tr>
<td>Total</td>
<td>117</td>
<td>183</td>
<td>300</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ/European</td>
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<tr>
<td>Maori</td>
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<td>8.3</td>
</tr>
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<td>Pacific Islander</td>
<td>15</td>
<td>5.0</td>
</tr>
<tr>
<td>Asian</td>
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<td>1.7</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>5.0</td>
</tr>
<tr>
<td>Total</td>
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<td>100.00</td>
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<table>
<thead>
<tr>
<th>Procedure</th>
<th>Number of patients</th>
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</thead>
<tbody>
<tr>
<td>Myelograms*</td>
<td></td>
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<tr>
<td>- oil-based dye</td>
<td>117</td>
</tr>
<tr>
<td>- water-based dye</td>
<td>64</td>
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<tr>
<td>Epidural steroids*</td>
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<tr>
<td>Spinal trauma</td>
<td>9</td>
</tr>
<tr>
<td>Spinal surgery*</td>
<td>84</td>
</tr>
</tbody>
</table>

* Note: many patients will have had multiple procedures.

Arachnoiditis Sufferers, Action and Monitoring Society
New Zealand only data from the 1999 global postal survey of arachnoiditis sufferers were not available. A smaller unpublished survey study in 1998 of 69 New Zealand arachnoiditis sufferers, documented the prevalence of a range of symptoms including tiredness, pain, muscle disturbance, general symptoms and treatments.

From the data presently available it is not possible to estimate the New Zealand incidence and prevalence of arachnoiditis. Existing data sources are inadequate or incomplete. No New Zealand studies have been conducted providing even case-based incidence or prevalence estimates nor specific procedure-based complications data on arachnoiditis. It is not known whether estimates from literature of other countries are generalisable to New Zealand. The lack of accurate data remains a problem. The Ministry of Health does not have reliable data to address support organisations concerns who believe the incidence and prevalence of clinically significant arachnoiditis to be high. An accurate estimate of incidence and prevalence would require population-based surveillance monitoring, perhaps involving mandatory disease notification. This is not feasible in view of the extensive resources required for a relatively rare condition and the difficulties outlined earlier with case records and clinical coding. Monitoring of a more general range of back pain and/or neurological conditions would have greater perceived benefits.

**Possible approaches to ascertaining the true prevalence of clinically significant arachnoiditis in New Zealand**

A review of public and private hospital records to identify the number of cases of clinically significant arachnoiditis as an iatrogenic event resulting from myelogram, discogram, epidural injections and other known cause procedures. Such a survey is not feasible, as this would be a huge undertaking, especially if a proper 10 year or longer retrospective analysis were undertaken. There are also problems with diagnostic definition labels of clinically significant arachnoiditis conditions and inpatient diagnostic coding issues. Non-specific diagnostic labels such as Failed back Surgery Syndrome (FBSS) or Chronic Pain Syndrome (CPS), and sometimes arachnoiditis are likely to have been used. However, this latter term has tended to be avoided. Also difficulties in obtaining access to private hospital records, ethics approval and cost for a relatively rare condition present significant obstacles to rule this out.

A survey of specialists (neurosurgeons, orthopedic surgeons, anesthetists, and pain management specialists) who perform such procedures as listed above. A review of case records and patient follow-up could identify those with complications. A sample survey would need to ascertain the population denominator of those people who are at risk of clinically significant arachnoiditis as an iatrogenic event before a statistically valid sample survey could be carried out. Persons ever having had a procedure in question over a 10+ year retrospective period would be the sample population. The issues of obtaining access to case records, ethical approval, diagnostic definition, cost and follow-up of patients in a 10+ year retrospective time frame are huge and are not feasible given the relative rarity of this serious chronic condition.

Incorporation of specific or related questions into the next Statistics NZ and Ministry of Health sponsored national household and institutional survey of disability to obtain an estimate of clinically significant arachnoiditis prevalence. Currently Statistics New Zealand are in the field doing the household disability survey post-Census 2001 for the next Disability in New Zealand 2001/2 report. This second disability survey is largely based on the previous survey to ensure comparability. It is too far advanced for a survey question submission to be made. Another survey would be some five years away post-Census 2006. This survey provides self-reported disability information with very little information on diseases and conditions. The focus of this and other disability surveys is on the effect of disability on people rather than the specific cause. Disability category and type definitions were based on New Zealand disability survey and Ministry of Health disability categories and are compatible with those in disability support service. These disability categories include sensory, physical, intellectual, psychiatric/psychological and other (age-related). Disability definitions are also confounded by the various legal and administrative agency definitions found under various Acts of Parliament.
Disability categories and types are broad and non-specific and create classification problems for conditions such as arachnoiditis. Given the focus on the effects of disability on people rather than specific cause, the time lag and disability definitional issues, the disability survey would not be a suitable platform.

Making a formal submission to the New Zealand Health Survey Steering Committee for the inclusion of relevant questions in the next New Zealand Health Survey. The committee is currently reviewing the existing survey questions and the inclusion of new items. The self-reported prevalence of diseases or conditions were not covered in great detail in the 1996/97 Health Survey. Only conditions that were believed to have relatively high prevalence in the general population and were in the previous health survey were included. These were asthma, diabetes, high blood pressure, cardiovascular risk, injury and poisoning. Consideration of such a submission would need to balance the interests of the key stakeholders – Statistics New Zealand, the Ministry of Health and the DHBs, the NZ Health Strategy, competing submissions from other interest groups and survey consistency. Appropriate questions would need to be developed. Given that the condition is relatively rare and remains controversial this is unlikely.

**Summary**

A lack of reliable New Zealand data on the incidence and prevalence of clinically significant arachnoiditis and with no viable platform to obtain such data means that it is not possible to demographically measure the public health impact of this condition on New Zealanders. From overseas literature the condition is considered to be relatively rare and therefore one can only assume that such findings are in some way applicable to the New Zealand context.
References


