

REPORT

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ANTECEDENTS AND COMPLICATIONS OF SIXTY-FOUR CASES OF ADHESIVE ARACHNOIDITIS

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ABSTRACT

Sixty-four persons with adhesive arachnoiditis (AA) who were undergoing active medical treatment were surveyed to develop a clinical profile of those who have the disease. As a group, these individuals were female, middle-aged or older, and had multiple medical disorders besides AA. Following the diagnosis of AA and during medical treatment, these individuals developed multiple neurological complications indicating that anti-inflammatory treatment was not sufficient.

INTRODUCTION

Adhesive arachnoiditis is a chronic spinal inflammatory disease in which cauda equina nerve roots are fused to the arachnoid membrane.^{1,2} This disease is notorious for its severe intractable pain, neurologic impairments, and premature death.² In the 1800's it was often called a "devil's disease."

Therefore, adhesive arachnoiditis has been considered rare. Recent epidemiologic surveys of patients with back pain, however, estimate that between 1.75 and 2.75 million American adults have AA.¹ Its actual prevalence is unknown since it is underdiagnosed, undertreated, and often ignored as a clinical entity. Nevertheless, AA is now recognized as a painful disease that requires treatment.³⁻⁶

To date, little is known about the precise causes or factors that lead to AA or its complications. Although many reports of AA are in the medical literature, most reports are single cases or from decades past.⁵⁻⁸ Little is known about patients who are in today's medical practice. This study aimed to characterize AA and develop a clinical profile to assist its identification and treatment.

METHODS

Arachnoiditis Hope is a public service organization dedicated to research and education of adhesive arachnoiditis (AA). One of its public service projects is to review cases and suggest care to physicians, patients, and families. The project maintains the enrollment of persons with the disease. In January 2026, 64 cases reviewed from 2025 were administered a written questionnaire that included demographics, antecedent information, and post-diagnosis complications. This study was approved by the Institutional Review Board of the sponsoring agency of the Tennant Foundation. No medications or invasive procedures were administered.

BASIC CLINICAL INFORMATION

There were 50 women (78.1%) and 14 men (21.6%). Their ages ranged from 32 to 76 years (mean 59 years: SD±11.5). They had a mean length of the disease of 8.50 years (SD±9.17).

ANTECEDENTS OF AA

Study participants were asked what they believed caused their AA. (Table One) They gave the answers listed in Table One with spine surgery (33;51.6%) and epidural injections (12;18.8%) as

the most common events. Participants were also asked about their previous and current chronic diseases. (Table Two) The majority had degenerative disc disease (47;75.4%). Approximately one-third of the patients had a history of infectious mononucleosis (21;32.8%) and about a fourth had Ehlers-Danlos Syndrome (15;23.4%). Half (32;50.0%) of the patients had recognized autoimmune disorders.

POST DIAGNOSIS COMPLICATION

The study participants reported a plethora of conditions that developed after they were diagnosed with AA. (Table Three) Loss of lower extremity function was common as participants developed leg weakness/paralysis and needed walking assistance. Other major classes of complications include disc degeneration and impairment of the bladder, bowel, pelvic nerves.

DISCUSSION

This study represents a significant numerical pool of current patients treated in current medical practice. The most striking aspect of these patients is that they are predominantly female, middle-aged or older, and have multiple medical conditions besides AA. All patients had one or more chronic disorders such as autoimmune disease, Ehlers-Danlos Syndrome, or degenerative disc disease. Other reports have also found a preponderance of older age females who have many co-morbidities.^{2,5,9} Although many of the individuals in this study perceived that a medical procedure such as surgery or epidural injection caused the disease, there appeared to be an underlying disease that may have made the surgery or epidural injection a high risk.

Once a patient is diagnosed with AA, various complications can develop. AA is traditionally known as a chronic inflammatory condition, and the reported complications in patients suggest that inflammation generally remain uncontrolled and continue to cause progressive complications.

This study indicates that modern-day AA patients are female, middle to older and have multiple medical conditions. AA appears to be a result of multiple antecedent factors. AA is a chronic inflammatory disease that progressively causes a plethora of complications and requires aggressive anti-inflammatory treatment.

CONCLUSION

People with adhesive arachnoiditis are beginning to be regularly observed in pain treatment settings. A typical patient is a middle-aged to older female with not only the spine, but also other medical disorders. Patients reported the development of many neurological complications that occurred after a diagnosis of AA. This suggests that inflammation is a significant component of the treatment.

<u>Table One</u> <u>Patients Perception of Cause of AA</u>		
1	Spine surgery	33 (51.6%)
2	Epidural injection	12 (18.8%)
3	Injury/accident	7 (10.9%)
4	Blood patch	5 (7.8%)
5	Idiopathic-unknown	5 (7.9%)
6	Infection	2 (3.1%)

<u>Table Two</u> <u>Previous or Concomitant Medical Conditions</u> <u>(More than one prior condition may be listed per participant)</u>			
	<u>Condition</u>	<u>N</u>	<u>%</u>
1	Disc bulging/herniation	47	73.4%
2	Infectious mononucleosis	21	32.8%
3	Ehlers-Danlos Syndrome	15	23.4%
4	Fibromyalgia	12	18.8%
5	Autoimmune – unspecified	11	17.2%
6	Hashimoto's	8	12.5%
7	Sjogren's	5	7.8%
8	Rheumatoid arthritis	3	4.7%
9	Tarlov cysts	3	4.7%
10	Psoriasis	3	4.7%
11	Lupus	2	3.1%
12	Scoliosis	1	1.9%

Table Three
Post Diagnosis Complications
 (More than one prior condition may be listed per participant)

	<u>Condition</u>	<u>N</u>	<u>%</u>
1	Leg weakness/paralysis	49	76.6%
2	Bowel issues	45	70.3%
3	Urinary dysfunction	44	68.8%
4	Burning feet	39	60.9%
5	Blurred vision	34	53.1%
6	Degenerative disc disease	32	50.0%
7	Headaches	32	50.0%
8	Tingling/numbness	31	48.4%
9	Cane/walker use	28	43.8%
10	Cervical discs	23	35.9%
11	Twitching/spasms	22	34.4%
12	Pudendal symptoms	19	29.7%
13	Loss of mental capacity	17	26,6%
14	Vertigo	15	23.4%
15	Wheelchair use	15	23.4%
16	Impotence	3	4.7%
17	Syringomyelia	1	1.6%

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