



INTRODUCTION

Complex regional pain syndromes (CRPS), formerly referred to as reflex sympathetic dystrophy and causalgia, are neuropathic pain states that continue to be therapeutic challenges.¹ Although these syndromes were described decades ago, their epidemiology has not been well studied.

The incidence, prevalence and natural history of this syndrome as well as the profile of patients suffering from the disease is uncertain. Knowledge of the demographic distribution, e.g., age, gender, race, and occupation, is based on small sample sizes.^{2,3} Moreover, the clinical approach to a patient suspected to have CRPS is complicated by a lack of precision of diagnostic criteria and minimal evidence-based information on treatment options.

OBJECTIVES

The goal of the study was to implement an Internet-based survey to provide additional information on the epidemiology of CRPS.

METHODS

Subjects diagnosed to have CRPS by their treating physicians provided information through a questionnaire posted at the Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA) website. CRPS patients were invited to participate in the survey, hosted for 6 months from October 2004 to February 2005 (www.rsdsa.org).

Reminders were sent through e-mail to members of RSDSA encouraging individuals to participate in the study.

The 75-question survey was guided by gaps in the epidemiology of CRPS and a list of e-queries to the RSDSA website during 2 prior years.

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1 Demographics of study patients N = 1359

Age (yr):	25 – 34 = 11.8%;	35 – 44 = 29.1%
	45 – 54 = 37.1%;	55 – 64 = 12.1%
Duration of disease 40 ± 58 months		
Gender	Male – 16%	Female – 84%
Ethnicity	White – 93.5%	Non-white – 6.5 %
Main regions (states)	California – 9.3%	Pennsylvania – 8.6%
	Florida – 7.9%	
Course of disease	Hx of remission – 21.3%	Currently in remission – 18.3%

2 Inciting event

The initial injury that resulted in the development of CRPS signs

and symptoms were:

- Surgery – 29.3%
- Fracture – 15.1%
- Sprain – 11.1%
- Crush Injury – 10.4%
- Others – 34.1%

3 Current frequency of common symptoms

At the time of the diagnosis, subjects indicated the presence of the following symptoms:

- Pain – 96.3%
- Swelling – 68.4%
- Increased sensitivity – 79.6%
- Change in color – 63.2%
- Difficulty in moving affected region – 78.1%
- Inability to use affected limb – 47.4%

4 Various factors associated with increased pain (percent of subjects)

- Physical stress – 92.4%
- Emotional stress – 82%
- Hot weather – 41%
- Cold weather – 88%
- Lying down – 26.5%
- Moving the affected area – 84.4%
- Working – 83%

5 Spread of CRPS symptoms/signs

- More than half the responders indicated spread of symptoms to a region other than the site of the original disease.
- In 24% the spread occurred in the same limb while in 18% the spread occurred in other extremities.
- Some of the common symptoms at the areas of spread were pain, swelling, increased sensitivity, difficulty in moving affected region and change in color.

6 Effects of pain on physical function and mood (% of patients)

The numbers indicate the proportion of patients with some problems with the performance of activities and alterations in mood:

- Mobility – 83%
- Self Care – 54%
- Usual Activity – 95%
- Anxiety – 76%
- Depression – 75%

Diagnosis/Treatment/Employment

- Physicians making the initial diagnosis –**
 - Orthopedic surgeons – 32%
 - Pain specialists – 19%
- Diagnosis made based on –**
 - Clinical examination – 45.7%
 - X-rays – 34.7%
 - Bone scan – 35.4%
 - MRI – 35.3%
 - Sympathetic nerve blocks – 46.4%
- Pain descriptors at the disease onset –**
 - Burning – 83%
 - Sensitive to touch – 80%
 - Sharp – 69%
 - Shooting – 57%
 - Aching – 56%
- Common drugs used to treat pain –**
 - NSAIDs – 63%
 - Gabapentin – 47%
 - Hydrocodone – 45%
 - Oxycodone – 39%
 - Cox-2 Inhibitors – 38%
 - Tramadol – 37%
 - Morphine – 29%
- Interventional therapies-**
 - Nerve blocks – 68%
 - Spinal cord stimulation – 5%
 - Sympathectomy – 6%
 - Physical therapy – 76%
 - Counseling – 37%
- Work**
 - Work-related Injury – 41%
 - Workmen's Compensation – 30.4%
 - Pain interfered with work – 93%
- Present employment status**
 - Disabled – 60%
 - Full-time employed – 16%
 - Part-time employed – 6%

CONCLUSIONS

- Internet-based surveys are potentially useful tools in obtaining epidemiological information of relatively uncommon diseases.
- Survey data suggest that CRPS commonly occurs in younger females and is often a consequence of surgery or work-related traumatic injuries.
- CRPS results in interference with sleep and functional activity, and suicidal ideations.
- The disease may have a prolonged course and progress to a different region despite treatment with multiple medications and interventions. The clinical features at the site of progression are similar to that at the original site.
- CRPS results in high incidence of disability from work.

REFERENCES

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