



## Epidemiology of complex regional pain syndrome: a retrospective chart review of 134 patients

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### Abstract

Complex regional pain syndrome (CRPS) remains a poorly understood chronic pain disorder. Little data has been published assessing the epidemiology of CRPS (and reflex sympathetic dystrophy, RSD). This study assessed epidemiological variables in 134 CRPS patients evaluated at a tertiary chronic pain clinic in the US, including demographic, health care utilization and legal/workman's compensation measures. In addition, the frequency of physician-imposed immobilization of the CRPS limb was assessed, as was physical examination evidence of myofascial dysfunction. This study found that these patients had seen on average 4.8 different physicians before referral to the pain center and had received an average of five different kinds of treatments both prior to and during pain clinic treatment. The mean duration of CRPS symptoms prior to pain center evaluation was 30 months. Seventeen percent had a lawsuit and 54% had a worker compensation claim related to the CRPS. Fifty-one patients received a bone scan, but only 53% of which were interpreted as consistent with the diagnosis of RSD/CRPS. Forty-seven percent had a history of physician-imposed immobilization, and 56% had a myofascial component present at evaluation. The duration of CRPS symptoms and the involvement of the upper extremity was significantly associated with the presence of myofascial dysfunction. Thus, this study found that most CRPS patients are referred to a pain specialty clinic after several years of symptoms and many failed therapies. The data also suggest the lack of utility of a diagnostic bone scan and highlight the prominence of myofascial dysfunction in a majority of CRPS patients. © 1999 International Association for the Study of Pain. Published by Elsevier Science B.V.

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### 1. Introduction

Complex regional pain syndrome (CRPS) remains a poorly understood chronic pain condition with regards to pathophysiology and treatment. In addition, little has been published regarding the epidemiology of CRPS and its predecessor, reflex sympathetic dystrophy (RSD). Studies have assessed several epidemiological measures of causalgia (CRPS, Type II), but this work was performed on war vic-

tims and not general civilian populations (Bonica, 1990). One large prospective study examined the symptoms and signs of 829 RSD civilian patients referred to a tertiary surgery clinic in the Netherlands (Veldman et al., 1993). However, none of these studies assessed health care utilization, legal, or worker compensation issues. A case series of one physician's patients diagnosed with 'chronic pains associated with various (and variable) combinations of negative and positive sensory, motor and vasomotor phenomena' was published, which briefly described socioeconomic and health care utilization data (Ochoa et al., 1994). The goal of the present study was to conduct a retrospective chart review of CRPS patients referred to a university-based tertiary chronic pain clinic in the US with the intent to describe this patient population's demographics, health care utiliza-

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garbage collectors. In 5% of the cases, the occupation could not be determined from the chart.

### 3.5. Legal and worker compensation issues

Twenty-three (17%) patients' medical records reflected either current or previous involvement in a lawsuit in relationship to their CRPS. Seventy-two (54%) of the patients had a worker compensation claim related to their CRPS. Twenty-three percent of the patients reported having undergone an 'independent medical examination' at some point at the request of legal or worker's compensation authorities.

### 3.6. Season

The season of the year in which the injury leading to the development of CRPS occurred was analyzed. Although not statistically significant, injuries appeared to be slightly more common during the summer months (27%) as compared with injuries occurring in winter (21%), spring (24%) and fall (19%).

### 3.7. Prior evaluations

Data regarding the number of prior physician consultations for CRPS symptoms were available in 113 patient charts. For these patients, the mean number of different physicians that evaluated the patient's symptoms before being seen at the pain center was 4.8 (range, 1 to 20). The most common types of physicians that actually referred the patient to the pain center were orthopedic surgeon/general surgeon (33%), anesthesiologist (15%) and neurologist (13%). Other specialties referring patients to the pain center included rheumatology (8%), rehabilitation medicine (6%) and podiatry (5%). Only ten patients (7%) were referred from their primary care doctor. In 13% of the charts, the referring physician could not be determined.

### 3.8. Bone scans

Thirty-eight percent of patients reportedly had a report of receiving a bone scan prior to or following their evaluation at the pain clinic. Of these patients, 53% were officially interpreted by the performing radiologist as having findings 'consistent with RSD' while 47% had a negative bone scan interpreted as 'not consistent with the diagnosis of RSD'.

### 3.9. Treatment (Table 2)

Each chart was examined for the number and types of treatments patients were given both before and during pain center treatment. On average, patients had been prescribed 5.2 (range, 2 to 8) different kinds of treatment, ranging from various medications to more aggressive treatment such as spinal cord stimulators. The majority of patients had received antidepressant medication, specifically 78% of

patients had received tricyclic antidepressants (TCA) and 38% had received selective serotonin reuptake inhibitors (SSRI); (it was not assessed whether these antidepressants were being prescribed for pain, sleep, or psychiatric disorders). Other pharmacologic agents patients had received included anticonvulsant (60%) and opiate (70%) drugs. Non-pharmacologic therapies included physical therapy (88%), occupational therapy (45%) and psychotherapy (50%). Nerve blocks had been given to 82% of patients with the mean number of nerve blocks being six (range, 0 to 38); the vast majority of nerve blocks were performed prior to pain center treatment. Eight patients (6%) had a spinal cord stimulator implanted to relieve symptoms of CRPS.

### 3.10. Immobilization

Sixty-four (47%) of the charts mentioned a history of physician-imposed physical immobilization following the injury with a cast or a splint. The mean duration of immobilization was 3 weeks, with a range of 1 to 24 weeks. Other forms of immobilization, such as patient-imposed restricted movement due to pain, guarding and motor-neglect were not consistently evaluated during the medical visit and hence no data is available on this variable.

### 3.11. Myofascial component

Fifty-six percent of the patients had a documented myofascial component associated with CRPS, based on the physician's examination for trigger points. The presence or absence of a myofascial component was determined by palpating for myofascial trigger points in the proximal musculature, such that when trigger points were present they reproduced some or all of the patient's RSD/CRPS reported symptoms; in upper extremity CRPS, shoulder girdle musculature was palpated and in lower extremity CRPS the lumbar paraspinal and gluteal musculature was palpated. Twenty-seven of 65 (42%) lower extremity CRPS patients had evidence of myofascial dysfunction, as compared with 40/58 (69%) of the upper extremity patients, a statistically

Table 2

Number and percentage of patients receiving each of the treatments examined

Treatment	Number of patients	Percentage of patients
Immobilization	64	47
TCA's	105	78
SSRI's	51	38
Anticonvulsants	81	60
Opiates	94	70
Physical therapy	119	88
Occupational therapy	61	45
Nerve blocks	110	82
Spinal cord stimulation	8	6
Psychological treatment	68	50

significant difference ( $\chi^2 = 9.30, p < 0.01$ ). In addition, the longer the duration of CRPS symptoms the more likely the patient was to exhibit a myofascial component ( $t = -2.73, P < 0.01$ ); the mean duration of symptoms in patients with the presence of myofascial trigger points was 35.4 months (SD = 29.24) and those without myofascial trigger points was 22.8 months (SD = 22.20).

#### 4. Discussion

Minimal information has been published regarding the epidemiology of complex regional pain syndrome (CRPS), and its precursors reflex sympathetic dystrophy (RSD) and causalgia. Besides having an unknown pathophysiology, scant information is available describing the types of patients that develop CRPS and the types of health care services rendered to treat this disorder. Some basic demographic data has been published (Veldman et al., 1993), but minimal information exists regarding patient occupation and medical consultation and therapies received by these patients. This study assessed these measures in a group of 134 consecutive CRPS patients referred to a tertiary chronic pain clinic in the US.

Several of the demographic measures obtained in this study are similar to those observed in previous studies. Our data shows a 2.3:1 female preponderance, similar to others' ratios of 3:1 (Veldman et al., 1993), 4.5:1 (Schwartzman and Kerrigan, 1990) and 1.6:1 (Ochoa et al., 1994). Our study, like several others (Mailis and Wade, 1994; Ciccone et al., 1997), found an overwhelming majority of those affected by CRPS are Caucasian. It has been hypothesized that there may be a genetic predisposition to the development of RSD following bodily injury, based on the finding of a clustering of the DR2(15) antigen in a very small cohort of RSD patients with a poor clinical outcome (Mailis and Wade, 1994). However, this ethnic data needs to be interpreted cautiously since patient-selection bias may be significant; the greater Seattle region, from which our study's patient population is composed, is approximately 80% Caucasian. Similar to a prior report (Veldman and Goris, 1996), the average age at time of injury that resulted in the development of CRPS in our patients was 37.7 years. The mean duration of CRPS symptoms prior to pain clinic evaluation was 2.5 years, a disturbingly long duration, especially since current experience suggests aggressive early treatment improves outcome (Bonica, 1990); the vast majority of these patients did not have intensive multidisciplinary therapy prior to pain clinic consultation.

This retrospective chart review is the first study to obtain certain epidemiological data in patients referred to a tertiary pain center and diagnosed with CRPS, including health care consumption and worker's compensation issues. Prior to evaluation at the tertiary pain center, the mean number of different physician consultations was 4.8, with some patients having had up to 20 evaluations. A similar number

of prior consultations was described by a 'neuromuscular unit' in patients given the diagnosis of 'chronic pains associated with various (and variable) combinations of negative and positive sensory, motor and, vasomotor phenomena' (Ochoa et al., 1994). Interestingly, the most common physician-type to refer a CRPS patient to our pain clinic was surgeons, 33%, whereas only 7% were referred by the primary care physician. This lack of direct referral from primary care physicians may be explained by several possible factors, including the potential poor diagnostic ability of primary care physicians, the changes in the American health care system, whereby managed care insurers are reticent to allow primary care referrals to 'pain clinics', or, on the other hand, may be due to a patient selection bias, with only the refractory patient being referred to a tertiary pain clinic. Regardless of cause, the delay in proper diagnosis and treatment of CRPS may have a negative effect on patient outcome (Bonica, 1990).

Therapies rendered to this group of CRPS patients prior to and during pain center treatment included varied modalities. The average number of different types of treatments patients received was five. The most common treatments provided included physical therapy (88%), nerve blocks (82%), tricyclic antidepressant medication (78%), opiate medication (70%), anticonvulsant medication (60%) and psychological treatments (50%). One other report described the frequency of therapies rendered to a similar group of patients and noted 68% had obtained physical therapy, 52% some sort of surgery and 26% sympathetic blocks (Ochoa et al., 1994). Our study's finding that 82% of patients had received an average of six nerve blocks (with one patient receiving 38 blocks) most likely reflects the community physicians' outdated training, i.e. the classical teaching that RSD is primarily treated with sympathetic nerve blockade (Bonica, 1990). However, this treatment construct is no longer the accepted gold standard, being replaced with the need for multidisciplinary approach, minimizing the role of sympathetic blockade (Stanton-Hicks et al., 1998). Clearly, practicing physicians need to be reeducated with reference to CRPS treatment.

The presence of worker compensation and litigation issues are felt to be common in many chronic pain conditions that frequently are associated with 'on-the-job' injuries, such as low-back pain (Fordyce, 1995). Although CRPS most commonly follows a bodily injury, to our knowledge only one prior report describes the frequency of such an injury occurring in the workplace. This prior report observed that 44% of its referrals were receiving worker compensation benefits and 18% were involved in court litigation relative to their painful disorder (Ochoa et al., 1994). Similarly, our study found that only 17% had a current or prior lawsuit regarding the injury that resulted in CRPS. More than one-half, 54%, had had their medical benefits covered by a worker compensation claim related to their symptoms. It should be noted, however, that this figure is biased due to the fact that the University of

Washington Multidisciplinary Pain Center has a contract with Washington state to evaluate and care for injured workers with chronic pain conditions. Our data is consistent, however, with another study which noted that 64% had a work-related injury resulting in their symptoms (Ochoa et al., 1994). This relatively high frequency of 'on-the-job' accidents precipitating the development of CRPS is not unexpected, since the most frequent cause of this condition is traumatic soft-tissue or nerve injury. Since CRPS is a chronic, often debilitating illness, these patient numbers most likely represent a considerable financial cost to society in patient time-loss benefits and medical care.

This study is the first to identify the types of jobs CRPS patients had while injured. Service occupations, such as restaurant workers and police officers, suffered almost twice as often from CRPS as other occupations. Manual laborers were the next highest group. The increased incidence of CRPS in these groups is likely due to the physical demands related to these jobs and the greater likelihood of an 'on-the-job' traumatic tissue injury. It may be that workers and employers in these fields need to take additional precautions to prevent 'on the job' injuries, and in the event of an accident, aggressive and early intervention seems to be warranted to limit the disability and cost associated with CRPS.

In addition to the epidemiologic data, some interesting clinical data were also ascertained from the chart review. Of the 51 CRPS patients that underwent a 'diagnostic' three phase bone scan, only in approximately one-half (53%) did the performing radiologist interpret the test as positive, i.e. 'consistent with the diagnosis of RSD (CRPS)'. This finding should seriously question the clinical utility of three phase bone scan in the diagnosis of CRPS. As this test appears to be non-specific, insensitive, expensive and does not aid in guiding therapy, three phase bone scan's role in clinical practice needs to be justified.

Other clinical information analyzed from the medical chart review were the incidence of physical immobilization prior to and the presence of myofascial dysfunction during the pain clinic consultation. Almost one-half, 47%, were physically immobilized, such as with a cast or splint, following their inciting injury as part of their treatment. Similarly, Schwartzman and Kerrigan (1990) found 42% of their RSD patients had been immobilized. The frequency of immobilization of the CRPS limb is most likely even higher, if one were to include patient-imposed immobilization due to protective guarding of their limb or motor neglect (Galer et al., 1995). This surprisingly high frequency of immobilization may suggest, at least in some patients, that immobilization of a limb may play a role in the pathogenesis of CRPS. Two animal studies have demonstrated that immobilizing a rodent limb results in both the development of CRPS signs and symptoms and, additionally, results in dorsal horn alterations akin to that seen after experimental peripheral nerve injury (Maves and Smith, 1996; Ushida and Willis, 1996). A small clinical study found that signs and

symptoms of CRPS develop in casted orthopedic patients following uncomplicated surgery (Butler and Galer, 1996).

This study also suggests patients with CRPS of the upper extremity and of longer duration are statistically more likely to have evidence of myofascial dysfunction on examination. These results extend a prior report's findings, which included a smaller ( $n = 43$ ) cohort of these patients (Rashiq and Galer, 1998). Based on the finding that the duration of CRPS was associated with the presence of clinically relevant trigger points, it may be postulated that myofascial dysfunction develops secondarily over time due to pain and disuse of the involved limb. However, due to the retrospective nature of this study, a primary role for myofascial dysfunction, i.e. myofascial dysfunction is the initial pathophysiologic event that actually causes CRPS, cannot be ruled out in some patients. Regardless of whether primary or secondary, physicians and patients need to be educated on the importance of early and gradual mobilization following soft-tissue injury, especially following surgery or trauma. Physicians should also evaluate CRPS patients for the presence of myofascial trigger points and treat appropriately when present with physical therapy and other modalities (Stanton-Hicks et al., 1998).

As with all retrospective chart review studies, the data presented are limited. First, data were not collected prospectively in a standardized fashion. Second, data for each variable was not available in every chart and, therefore, the percentages reported may be a misrepresentation of the true values. Third, the patient population studied was only of those patients referred to a university based tertiary chronic pain clinic in Seattle, Washington, USA. Similar studies need to be performed in other clinical settings, such as non-university based pain clinics and in other countries. It is likely that CRPS patient populations evaluated elsewhere possess different characteristics and different therapeutic approaches are prescribed.

In conclusion, this retrospective chart review study has described the demographics and health care utilization of CRPS patients referred to a tertiary pain clinic in the US. Multiple consultations and therapies are obtained by these patients prior to pain clinic referral. In addition, a substantial percentage of these patients have a history of limb immobilization and a significant myofascial component identified on initial evaluation.

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