
Editorial: I have a dream ... reflex sympathetic dystrophy (RSD or Complex Regional Pain Syndrome - CRPS I) does not exist

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Editorial*

I have a dream ... reflex sympathetic dystrophy (RSD or Complex Regional Pain Syndrome - CRPS I) does not exist

There is one way of having a whole community turn against you; that is by making a statement that is against accepted beliefs. "The earth rotates around the sun" is but one historic example. So, if I start my editorial by saying that I do not believe in the existence of reflex sympathetic dystrophy (RSD: for the younger - CRPS I; for the elder - Sudeck's atrophy), I am probably sparking a scientific outrage in our community. Some may even seek to burn me on the stake for heresy but, what if I am right? What if CRPS I is just a "fairy tale" we have made up to mask our frustration when unable to properly diagnose or treat our patients? What if diagnosing CRPS I is actually halting the progress of true science? What if the diagnosis of CRPS I is sheltering a lot of bad doctoring?

The first question you may want to ask me is why on earth a reputed surgeon, one of the Editors of this Journal, would wish to cause such a rumpus. I must admit I am not sure, but I feel that a younger surgeon will ruin their career in front of the Hand Surgery Community before even reaching the end of the first paragraph. Before I go on I should warn the reader that this is an editorial, not a scientific paper. Purposely I have not put in any references; there is so much literature to support almost any argument that it would only add more confusion. This editorial is the opinion of one surgeon, albeit shared by others, who seeks to challenge vigorously the current interpretation of a so-called "condition". I do not feel I am in the wrong by doing so: after all, our work as scientists is to challenge unproven knowledge. So even at the risk of being wrong, and putting my reputation at stake, I repeat: (CRPS I) RSD does not exist.

I hope by now I have firmly set the cat among the pigeons!

Weaknesses of the concept of CRPS I

Humankind almost always seeks to try to find an explanation for what we do not understand. Now that

we can no longer invoke the wrath of the Gods for our illnesses, CRPS I offers an unparalleled dustbin where all "difficult" problems/patients can be deposited. I do not want to say that people who study CRPS I are unscientific. Rather I fully acknowledge that there are an important number of investigators working on RSD (including three papers published in this issue). But, could these investigators be heading in the wrong direction? There are many examples of this in the recent history of medicine: just consider for a moment the extensive literature on somatization as the cause of the peptic ulcer and the thousands of vagotomies that have been performed to treat duodenal ulcers and yet the psychiatrist or vagotomies have no place today in peptic ulcer management.

Even the reputed scientists who work on CRPS I will agree with me that the disease is based on predominantly subjective diagnostic criteria shared by many other diseases and there is no specific test for CRPS I. To complicate the matter further, the diagnostic criteria and aetiology change every now and then (recently it was sympathetic mediated pain). All students of the subject agree that there is a hyper-response to a nociceptive stimulus that triggers a pain response....But, what if the stimulus is there and we have been unable to recognize it? That would radically change clinical practice since finding a cause automatically excludes CRPS I as a diagnosis.

I am amazed how the medical community is so stringent in diagnosing most conditions, but accepts the mysterious CRPS I: no aetiology; no clear-cut clinical signs or symptoms; no diagnostic test; and ineffective treatment protocols. Surely this too much to accept? Is it not remarkable that we accept a condition where the colour of the hand can range from red to white, passing from blue to purple all due to "neurogenic mediated pain"? Yet is not all pain neurogenic mediated? To complicate things more pain is subjective and the patient can feign it..... and worse, are not pain, redness and swelling the signs of inflammation? In fact if there were something irritating our hands/wrists, would inflammation and pain not be present? Are we not overlooking something?

One of the reasons that I question the existence of this condition is that most patients with CRPS I develop the condition after trauma/surgery. As a

surgeon who treats hand injuries and inflicts "injury" through surgery I do not see this condition in my patients. This is not to say that I do not have patients with pain after I have operated on them. Rather I search diligently for a cause and usually find one so that in the last 15 years I have not referred a single patient to a pain doctor. I do see patients for second opinions in the miserable throes of a "mysterious painful process" under the care of a pain doctor, who have not had adequate investigation /treatment. I find I can nearly always make a diagnosis and successfully initiate treatment.

If I were to put the previous paragraph in an accusing way it would read: how can we make a diagnosis that has such an enormous impact on a patient's well-being so frivolously? I had a professor at Medical School who used to say that: "Fever of unknown origin were more unknown for some students than for others" meaning that knowledge and understanding reduce drastically the number of cases of fever of unknown origin. In my experience the same applies to CRPS I: the less you know the more you resort to this diagnosis. CRPS I cannot be used as the convenient joker in the pack. A second corollary from the above is that CRPS I labelled as such by a specialist outside the realm of hand surgery (i.e. pain doctor, neurologist, rehabilitation doctor, not to mention physiotherapists or occupational therapists), is in my experience very likely to prove incorrect. The **only** person to who should reliably state that there is not an overt organic cause for a patient's pain should be the specialist in the field i.e. a **Hand Surgeon**.

Why it is bad to diagnose CRPS I

It is both bad science and may also be harmful. I (simplistically) divide patients into two groups: those with a problem; and those who wish to have a problem, when they have none (in their hands). Both need a doctor but in different ways. The first ones need the doctor to make a diagnosis and offer treatment, whilst the others need the doctor to find a non-existing condition that justifies their complaints. Both sets of patients are hurt by a diagnosis of CRPS I: The first are "prevented" from receiving treatment for the cause of their problem as CRPS I has "no treatable cause". The second group suffers from the nocebo effect: the opposite to a placebo. The nocebo 'gives/reinforces' in a patient a non-existent disease. We are all aware of malingers who feign a disease for secondary gain. This may be financial or psychological. These patients benefit immensely from a diagnosis especially one as non-specific as RSD.

Conditions that may mimic the symptomatic constellation of CRPS I

If you accept that this condition does not exist, then you will try to find an explanation for any patient who comes to see you with inflammation, pain and redness out of proportion of what you may expect. There are some conditions that go along with that, yet they are treatable. Among the most prevalent are:

- **Unstable fractures:** Historically, unstable fractures were the major cause of oedema, redness, stiffness and bone demineralization, which the people of the AO tried to tackle by using rigid fixation. Yet, the signs and symptoms of what was called fracture disease are exactly the same as those of CRPS I. Lack of stable fixation, poor fixation and poor fracture reduction are the main causes of incorrectly labelled CRPS I that I see in my practice for secondary consultation. Anatomical reduction, rigid fixation and immediate range of motion cures all of those "CRPS I" patients.

Because of its prevalence and the universal believe that Colles' fractures do well in a cast; my major group of "CRPS I" patients have had a Colles' fracture treated conservatively or fixed unstably or with an articular step-off. But is important to underline that any unstable fracture can be a source of pain, swelling, and redness.

A common pathology in this constellation are patients who have developed a so-called shoulder-hand syndrome. I find it astonishing that we could have come up with a condition around this. The explanation for this "syndrome" to me is clear: in a patient who sustains a fall, as well as the wrist trauma, the shoulder will also be involved. Underrecognition of the shoulder pathology, immobilization and the weight of the cast all contribute to stiffness, pain with motion, frozen shoulder and thus a "shoulder-hand syndrome". Yet there are quite plausible organic explanations in both regions.

- **Subclinical nerve entrapments.** This forms an important group of misdiagnosed CRPS I in my practice. There is certainly a wave of awareness that CRPS I can actually be a CRPS II (when a nerve is involved) and that carpal tunnel syndrome may be behind the painful condition that has been labelled as CRPS I. However, it is not so clearly recognised that without a positive EMG

the patient may respond well to carpal tunnel release.

- **Disvascular states** (Cold-Tobacco-Crush). Smokers heal poorly and with stiffness. This is not surprising, as it is well known that smokers have a diminished ability to heal any injury or operation and the hand is no different. In the skin, tobacco users heal frequently by secondary intention and bad scars are common. In the hand, lack of oxygen causes fibrosis and stiffness. Disvascular states of themselves are a source of pain.
- **Pain-triggering pathology.** Among the most well known occult causes of pain are glomus tumors. But other much rarer causes such as damage to the posterior interosseous nerve or atypical nerve compressions may be behind the scenes in CRPS I patients.
- **Psychiatric conditions, SHAFT and the like.** Be fully aware that there are malingerers, and that conversion disorders may mimic CRPS I. Both need us to fuel their process. CRPS I is ideal for their goals and it is down to us to prevent this from progressing further.

Weaknesses of this editorial

I cannot explain why some patients respond to injury with minimal symptoms and other very marked. Yet we recognise this in many areas of our practice but do not need to make a separate area of diagnosis to explain why some people for instance suffer marked pain following scaphoid non-union and need surgery and others only present aged sixty after a full working life with minimal problems.

I also accept there are some patients in whom I cannot make a diagnosis. I believe that time will enable me through the genius of other clinicians or through technology to make diagnoses that at present we cannot.

*The Editorial of a Journal is an opportunity for broader thinking even speculation, which will hopefully stimulate debate. Paco Piñal, one of our Editors, has written a personal view of CRPS, which is this month's Editorial for the Journal to coincide with three very interesting papers on CRPS from renowned experts. Paco's view is not the view of the Journal, where we accept the present classification of CRPS I and II. Nonetheless his point that CRPS I is over diagnosed without adequate search for other causes is recognised by many clinicians. His views will stimulate thought and I hope comment.

Grey Giddins
Editor-in-Chief

Conclusion

In my view, accepting that this condition does not exist may benefit patients enormously. By the same token, a clear disservice would be made to the patient and the progress of science by doing otherwise. We need to be much more self critical when assessing our bad results (not only those of others). It is our obligation as doctors to search for a tangible cause for what went wrong, as opposed to laying the blame on a mysterious condition. A taskforce is needed in order to critically assess the patients who have no obvious cause for their pain. I concede (very reluctantly) that there may be a number of patients with CRPS I. Nevertheless, taking into account the fact that I lead a busy practice and that I do not see patients without inexplicable pain, the incidence of CRPS I, if any, should be very rare.

I must confess that I dream that we have tackled the condition named RSD/CRPS I etc. and that the mystery and bad doctoring that hide behind the acronyms are over. I hope that my dream comes true and that soon what I now repeat ad nauseam to all my residents, fellows and visitors - "Reflex sympathetic dystrophy does not exist: search for the cause of the patients' pain!" - proves to be true. At this moment however I only look forward to receiving letters of criticism. But let us just imagine for a moment I am right ...What if this editorial is as logical as the fact that the earth is round and rotates around the sun? At least it makes more sense to me than to believe in fairies.

I hope to make some of you doubt.

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