Complex regional pain syndrome. A critical concern still?
David R Tollfield

These articles written by the author are intended to assist healthcare professional further. Please see sheet 12 under Clinical (rare) conditions on my website www.consultingfootpain.co.uk

Useful addresses

1. http://www.patient.co.uk/support/crps-uk-clinical-research-network

In 1999 the Liverpool Pain centre at Walton moved to a new hospital on the old Fazakerley Hospital site, now the University Hospital Aintree.

Patients may want to consider sources 1-3 and GPs sources 4-5 as an introduction

A view from a Consultant Podiatric Surgeon

I have been managing CRPS for some years, principally after foot surgery. The incidence of CRPS seems to be variable depending upon the source of any reflective study or audit. I have updated my original article for doctors and other MSK health professionals in order to heighten awareness. It might also be something the legal profession would do well to consider as they too can make the matter worse paradoxically!

The cause of CRPS is not always what is appears and while surgery may evoke the condition, the occult nature of the process lies in wait for a specific noxious stimulus to arise. My first experience came from a chronic ingrowing toe-nail in a 13 year of girl. Another arose in a 10 year boy who stubbed his toe whilst out playing. Children are less commonly affected than adults but we need to adopt a healthy suspicion no matter what our specialty is.

Feet, knees, hands and breasts are all anatomical areas exposed to this cruel condition; even in the 21st Century the best research alludes the ultimate treatment and cure. The principle features are pain outside normal expectations. A foot wound after surgery may take 2-3 weeks to heal, but has some reasonable strength at 6 weeks plus. Pain may be present for a variety of reasons up until this point. Heightened pain may accompany colour changes associated with vaso-motor changes. Purple mottling is often reported by the patient but is a sign not an absolute diagnosis. The foot being at a lower level experiences orthostatic pressures that can change the colour after surgery. Pain medication will have a beneficial effect on most patients, but unremitting pain that cannot be controlled for a minimum 4 hour period suggests other investigations are required. The window of opportunity starts to arise from 6-12
weeks in my own experience. Beyond this timeframe opportunities to manage this complex pain problem begin to become troublesome.

Upon healing the clinician can examine the foot carefully and if pain, or a fear of pain is noted, then nothing but light touch should be used. In fact some patients will not allow touch and the sheer proximity of the examiner’s hand is enough.

**So who is at risk?**

Much of my work now is trying to assess who might be exposed to CRPS. This is a tough one to get right given that we are all in business of helping patients as best we can. This means having to reject patients for surgery because the risk outweighs the benefit. Given that our work is elective, we are forced into a tight corner. This is ever becoming more vexed. It is a tough call but experience seems to correlate to the following features;

- **Female** (gender sensitive)
- **Depressed** (using medication of long standing)
- **Back pain** using analgesics (long standing)
- **Social stability and married status poor e.g divorced**

Certain groups of patients are more susceptible and the above criteria are not exclusive, e.g children and those of Asian background.

Conditions that are highly susceptible to post operative problems are mostly neurogenic in origin. These take the form of Morton’s neuroma or interdigital neuromata (metatarsalgia), tarsal tunnel and chronic posterior tibialis (or FHL) tendon inflammation with close proximity to the tibial nerve. Trauma to, or near a nerve can set of the process.

**Case History**

A delightful female patient attended my clinic some years ago with complex pain syndrome, but also with the problem of tarsal tunnel syndrome (TTS). A balance was made to proceed to manage the nerve by decompression, which does not invade the nerve but separates the space. She was under a pain clinic and was already taking gabapentin. The risk was notable and the pre-operative discussions were very detailed. Failing injections of corticosteroid she pressed me to operate. The operation went well in regard to the condition and I undertook all due care around the nerve. Her TTS settled but then she had an escalation of CRPS. I followed her for three years and saw her deteriorate. I think this case history highlights some of the aspects of making clinical decisions. No patient can use the phrase “Well I cannot be made any worse can I?” The response must be and many times especially with the misfortune of disability and immobility forcing aids such as wheel chairs onto an unsuspecting patient.

**Treatment**

The websites given below will show a variety of treatment but to date early use of tricyclic ant-depressant amitriptyline 10mg nocte with anti-inflammatory and neuroleptics remain our first line treatment, and should be introduced early. I work
closely with several pain management specialists (anaesthetists) so we have a robust protocol developed nearly seven years ago. Even with early treatment it can take 9 months to bring a modest CRPS to a level of acceptable living. The other measure of achievement is keeping the patient in gainful employment. Loss of a reason to contribute to society robs us of more than just an income.

Better publicity

Lynne Turner-Stokes and Andreas Goebel have contributed to the Royal College of Physicians guidelines on CRPS (2011). The updated version (2012) is larger and considers input from many professions. This is a salutary report that bears more realism than many and does not hold back the punches when it comes to unrealistic expectations. No MSK surgeon or health professional should be unaware of this report, which should be updated in 2016. Furthermore it comes from the stable of the Liverpool Pain Clinic4. In my 2005 article (below), the conference of the Reflex Sympathetic Dystrophy Help Group UK had the input from Bristol Pain Clinic’ Professor David Blake. For me this was an emotional learning curve which included 100 people, some who unwisely exposed themselves to lower limb amputation.

The quote of 1 in 1000 or 4 in 2000 all seems a nice figure but data coming back now suggests higher occurrence rates. That is higher in the milder stages. Take care of the ‘mild’ and you may just stand a chance to avert the ‘full blown’ CRPS. This must be our true aim. Lost time means lost opportunity. True enough, full blown CRPS as we like to call it is less common 26/100,000 (RCP Guideline 2012).

‘Full-blown CRPS’

Full blown CRPS pretty much has the picture of fixed contracture, pain, colour changes, tissue changes and active sweating with thermal features of a cool useless wasting foot or limb. Given a general anaesthetic a patient with all these features reverses to normal colour, no fixed deformity, and then returns to the bizarre features stated above within 10 minutes after return to consciousness. Such limbs cannot be splinted and accelerate symptoms requiring morphine. Physiotherapy has to be sensitive to movement and the key objective is to fool the brain and desensitise the nerve endings.

Unfortunately the limb itself is not the only part affected as patients are disbelieved by friends, family, work staff and healthcare people. They become distressed, are easily affected by noise, and unpleasant sensations elsewhere such as the erogenous zones. Such stimulation under normal expectations should be pleasurable but is heightened in full blown CRPS and the sensation is far desirable. Sleep is disturbed and patients often dream bizarrely about amputation of the affected part or suicide. These latter questions may relate to late stage and intractable CRPS.

Management beyond drugs

Management is not about pharmacy alone but about self help interventions, education, desensitization of the limb, support from sensitive clinicians and psychological support. Drugs are vital to control aspects of the condition. The NHS is poorly geared to undertake this as budgets are contained to attracting the big health themes, and then toward making money for their Foundation Trusts! The private sector is even worse
because insurers do not bear the cost for chronic conditions for the reasons of how price scheduling is framed. These are areas that can be changed, but only by influencing the people at the top to make them understand. Big centres such as Liverpool and Bristol are poorly supported and rely on raising their own funds.

Insufficient health care practitioners are aware of the fundamental changes that arise. In 1978 I learned about Sudek’s atrophy. 10 years later I saw my first case. I believe I did not know enough as a young podiatrist to spot the mild signs.

Looking at national podiatric surgery data we arrive at 0.17% for 17,319 podiatric surgery patients. Most do not have the bizarre signs stated above. For my own centres following audit of 883 patients this shows as 1.35%. The difference is nearly eight times higher. But even this data used a nurse led clinic where not all cases were recorded accurately as I would have. Is my practise worse than others? Well it comes down to clinical diagnosis and accurate recording and severity. I tend to record milder forms as well as moderate and severe. Where I am the sole evaluator of my own clinic this figure rises further to 2.17%.

These outcomes have to be rigorously recorded if we are to establish the true risk. In both the NHS and Private sector if post-operative management is relegated to earlier discharge we are likely to miss more occurrences. GPs will have to pick up the signs more and act. Some of this comes down to better education and good clinical integrity from those of us that undeniably are in the forefront of the condition. One thing is certain; in the UK, CRPS is under reported.

Lack of early recognition. Please read my article below (reported in Podiatry Now, 2005) will lead to disabling consequences.

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Complex Regional Pain Syndrome: Why should we be aware?

David R Tollafield (Podiatry Now 2005)

Abstract

During 2005 I reported on two conferences to highlight the effect of complex regional pain syndrome on both the patient and the treating clinician. New treatment is being researched using mirror therapy. Some of the earlier pathways of pain seem to have a closer association with the hippocampus (limbic system) where emotional response is part of the function. This account does more than just provide an overview of the condition, as it considers the fallout of a relatively poorly understood affliction without prior warning. The reason for drug therapy failure may be because associated with the lack of specificity in targeting the correct centre of origin

Introduction

RSD, (reflex sympathetic dystrophy) is now known in medical circles as CRPS. The short form stands for complex regional pain syndrome. Coined by the International Association for the study of Pain (IASP) in 1993 but dates back to the first cases identified in 1862 during the American civil war. Any injury can cause the problem. I have seen a 10 year old develop the problem following a knock against the pavement curb. Full blown CRPS is thankfully rare, but symptoms can become intractable and treatment not always successful. Litigation often follows CRPS if associated with elective surgery – for someone has to pay. The surgeon is more exposed to the risk than perhaps the physician.

Whether we consider the Hippocratic oath relevant to podiatry or not, the adage that we should do not harm and certainly not make the patient worse, must be an sure fast aim of all podiatrists. Each year however, podiatrists and other healthcare practitioners harm patients, albeit not intentionally. Okay we all know that this is not new news, and neither is the huge amount in compensation paid out by the NHS news. What is news though is that society still has a poor understanding and knowledge about a rare condition that is more common than you would imagine.

During the course of last year (2005) I was involved with two conferences; one a professional conference of podiatric surgeons (Grantham), the other a conference for the group RSD(UK), held at Wakefield. Although the latter conference was held later on in the year, I would like to invert the order and report about the Wakefield conference first. I will share some observations and home truths about a condition, which leaves the patient angry. They (the victim of this condition) are left disillusioned with the healthcare establishment and help system - namely the Department of Works and Pensions. Seemingly even the press have not given any time to consider the devastating effects of RSD/ CRPS on the victims of this destructive chronic affliction.

The conference – Wakefield (Patients)
I was delighted to be asked by the group organisers, Catherine Taylor and Barry Swallow, to speak to the conference on this condition. Due to the sheer diversity of names this has now been redefined as complex regional pain syndrome. Actually it is divided into type I and II. This comes as no surprise as many podiatric-orthopaedic conditions are typed with one or more options. This makes learning that much harder when we are students. The type of classification is not important here though, as the signs and symptoms are not dissimilar, just the potential cause.

RSDUK is the only self-help British organisation that is dedicated to the patients and sufferers of this condition, run by patients. It is run voluntarily as a charity and like so many good causes, it is desperate for money to help its members. Members pay no direct fee, although they can volunteer. As with most conferences, a spacious hotel room was organised but the need for bedroom access for disabled persons was a mite tricky. Few hotels seem to have allocations of plentiful rooms suited to disabled needs, and so choices are limited, hence the Cedar Hotel off Junction 39 was selected. I was dismayed at how many delegates were confined to wheel chair use. In fact this was the first sign that greeted me on the Friday night of my arrival, that and the smoke from cigarettes which hung thickly in the atrium of the hotel. Men and women were huddled into groups. Smoke drifted toward the main automatic door as it slid open and shut with passing traffic, reminiscent of Brownian motion. On the day of the conference, I was due to speak at 11.40 that morning and went in early to check that the AV system was manageable. The conference room was nearly full before the allotted start time of 9.30 and this was just a touch after 09.00. If only our professional conferences could start so punctually! Like many colleagues, I have seen, treated and created the problem inadvertently. I know a little bit about the condition but little did I know how much more knowledge I was to acquire by the end of this Autumnal mid-September day.

Dr David Barton was conference chairman and apart from being gifted as a man with a rare talent for making the subject light without patronisation, he had struggled bringing up his 10-year-old son suffering from CRPS over the last 8 years with his wife. David Barton addressed the conference delegates telling them that at any time if they felt unwell they could leave, and if they felt the need to go for a sleep just to slip away. I surveyed the room curiously. It was filled with patients with mixed emotions set on their faces. One young woman was in a constant flood of tears and clung onto her partner through most of the time that I saw her during the weekend. Each step was agony. I gave up counting the wheel chairs. Most delegates had feet exposed or simply covered with socks to avoid any pressure or just to keep their extremities warm. Most wore some bootee on the foot or a glove on the hand. I did not see any Black or Asian faces - just white, mostly female, aged between 18 and probably 75 something. Some patients had hand splints, some had leg splints and most used an aid such as a crutch. Most seemed supported by a friend or partner. One woman (probably around 30-years of age) had had a full limb amputation at the hip level. Although she looked cheerful she was far from pain free. The effect that the room had on me reminded me of the aftermath of a war zone. Some of those attending had an unnatural glaze effect on their face, perhaps more associated with being told of sudden calamity.

While all the speakers were excellent, it was the tall charismatic form of Professor David Blake who was there to put the nuts and bolts together and was the star of the show. David is a Consultant Physician and Rheumatologist at the Royal National Hospital for Rheumatic diseases in Bath. He is patron of RSD(UK) and has more than
a passion for the subject of CRPS. David announced quietly (to me) that he would be surprised if at some point during the day if a delegate did not stand up and give an outburst. He explained these are very angry people. If they became antagonistic just let David Barton sort it out. I declined any bet wagered, but swallowed a bit harder anticipating a gruelling time after I had presented my lecture; it was just an innocuous subject really, ‘The role of podiatric surgery in the cause of RSD/CRPS’. My opening statement was, “I am one of those that causes this condition, although of course unintentionally”.

Someone from the Department of Works and Pensions spoke before me and maybe he took the brunt of the questions. No one messes around with patient’s money and expects to get away with it. In this audience there were about one hundred potential hostiles. At any rate I survived and allegedly I was told they liked my honesty up front. However, although none of my patients attended the conference there were two patients who had had podiatric surgeons operate on them – both from London. Sadly, one of the cases was not diagnosed by the podiatric surgeon, but by a rheumatologist. The purpose of the (earlier) Grantham surgical meeting had been to inform the profession that each of us has a duty to recognise this condition. It is unreasonable that following past publicity that we cannot diagnose this condition ourselves. This is a highly visible question often set at the Fellowship examinations in foot surgery.

Both the postoperative cases at Wakefield were associated with interdigital neuromata – a common nerve swelling pinched off between metatarsals. Two-second year students from the local Huddersfield school attended. This was a wonderful representation from a student body and a triumph to see motivation so early on. I don’t have exact figures but it seemed that delegates were equally distributed between feet and hands, more females than male sufferers.

Professor David Blake fielded many questions during the day. The audience turned out to be more than tolerant and although there was much tooting and frowning, the main body of the room seemed full most of the time. One poignant question was associated with “how rare is it to be affected by CRPS in the opposite limb?” The delegate informed the Professor that her consultant had indicated that it was rare. He promptly turned to the audience and asked for a show of hands how many were affected on both sides. Astonishingly, as if punching into the database of a computer, the answer was revealed. Something like 75% of the audience were affected bilaterally. Live evidence is rare but that is what we were treated to.

The audience filled in a very copious questionnaire filled with diagrams and simple statements. The area of drug usage and effectiveness was revealed. Most had found that drugs had not had any significant benefit on their condition. I think that this observation needs to be qualified. For those delegates that were chronic long-term sufferers, the benefits may obviously be diluted. In no way would we consider that the pharmacological approach is inappropriate, although treatments such as acupuncture, TNS, reflexology and physiotherapy will have varying benefits. No one strategy is going to be repeatable or offer a panacea. The direction that research has taken then suggests that a higher centre of sensitivity is associated with maintaining signs and symptoms. Worse still for the sufferer of this seemingly intractable condition are the bizarre series of problems, certainly not commonly expressed in the literature. Spatial changes affecting the hippocampus region of the brain and limbic system lead to aura, disorientation and parallel symptoms in other parts of the body. CRPS in hands may lead to pain and sudden hot areas on the face. So for instance, someone inadvertently
grabbing at a sufferer’s hand could cause a reflex on the face with a change of temperature. CRPS sufferers find that there is a safety zone around their affected limb and should this space be invaded, then the sense of panic is amplified. Any clinician who appreciates that this level of hyperalgesia exists will not make sudden movements or touch the limb injudiciously. The lightest of touches can bring about significant distress. There seems to be an increased sensitivity to many of the senses, although curiously smell is not one. Sound and certain shapes may cause an exacerbation of discomfort or even emotion. Certain geometric shapes will flicker when viewed. Sometimes the movement is just gentle when the eye focuses on the optical illusion of a square changing from one dimension to another. Such flickering does not bother the normal brain, whereas Professor Blake showed that CRPS sufferers could be alarmed by sudden exacerbation of anxiety if the box moved too rapidly.

For any clinician treating CRPS, physiotherapy is important and immobilisation undesirable. Aggressive physiotherapy can make the limb worse and physiotherapy cannot begin until the brain will accept movement by being desensitised. Use of a mirror can help this to be achieved. The affected foot/hand is placed behind the mirror and the good limb is viewed. The brain is fooled into thinking that it is the opposite limb affected by CRPS. The limb is moved by suggestion before it is actively moved. In other words, the brain is being taught how to recondition itself to a point where the amplification of activity is reduced. This process may takes months but it is regarded as ground breaking as far as understanding the how to treat and reprogramme the part of the brain which is affected. Suffice it to say that physiotherapy cannot commence until touch and movement is tolerated. Gloves are used and socks to desensitise the skin and prepare the hand/foot for movement. The action of just pulling these pieces of clothing over the limb can be beneficial, but only once the mirror work has progressed. If the hippocampus were at fault then it would explain why many drugs fail to help. In each case the pharmacological pathway could be incorrect and so we must await a new generation of drugs that might be more specific to turning off the signal. I like the analogy used by a pain specialist at a Podiatry conference in 2000 (Warwick University) – the condition arises where the pain tap fails to turn off after an injury. Simple but graphic.

I was asked to take part in a clinical sketch scenario. David Barton took the role of the GP and deliberately showed lack of interest and knowledge. Poor communication skills were ruthlessly exhibited to show the effect on a patient with 6 months of an undiagnosed CRPS. Sally Womersley a professional role-play actress that we had used at the Grantham conference took part. She was able to reflect a sense of significant realism for the audience; not least because she could create all the emotions seen with the CRPS condition. Sally limped off none the wiser and in great distress. The audience even found some laughter in this sketch, but not so when I played the GP who had some sensitivity. So much was the realism of Sally’s playacting that the audience were distressed, not least because we had not mentioned that she did not exhibit any of the signs and indeed was effectively normal at the start. Some of the delegates had to leave and were visibly moved to tears. Because of the emotions and indeed the degree of empathy intended in this counter sketch to illustrate different approaches, the second scenario had an effect none of us expected. The high degree of sensitivity to emotional response from any such stimulus makes this condition unique given that most injuries are very much more amplified compared to the original injury or stimulus.
It can be expected therefore that patients with CRPS may have far reaching problems. During the Grantham conference the key objectives were to indicate that early diagnosis supported with early treatment might do much to allay the gross signs of the condition. The importance of consent has become a professional issue with podiatric surgeons realising that CRPS should be included in the consenting process for majority of procedures. While I personally do not believe that ingrown toe nails (IGTN) have been involved directly in the creation of CRPS, each practitioner must use his own judgement when consenting. A patient faced with the prospect of even a slight chance of CRPS might prefer to know. However, ALL patients submitting to neurectomy MUST be informed as the potential could run from 1-5% chance. The same potential could be raised with other nerve surgery. Harris, Fallat and Schwartz 2004 published data on the incidence of CRPS. The chance of the condition affecting white females seems slightly higher. The winter season and those engaged on moderate heavy work could be more exposed. The paper is not one that could be described as of high scientific significance and yet any information can be helpful if it makes us question likely aetiology. Several annual podiatric conferences have included CRPS and we can no longer hide our ignorance. Harris’ paper is weakened, as I suspect it fails to look at low class America with it’s poorer population. Equally in Britain we may be persuaded that females are more likely to suffer from the condition than males based on the premise that podiatry deals with far more females.

Just in case the non-surgeons think that CRPS remains in the domain of the surgeon, think again. I have seen symptoms in a runner who developed the problem after a marathon. Orthoses were implicated but probably had only a slight chance of causing an exacerbation. I have seen the condition in pre-operative tarsal tunnel syndrome and also posterior tibial dysfunction. To make the reader even more cautious patients may develop this condition from fasciitis or any soft tissue inflammation associated with tendons and strain. Idiopathic CRPS can arise without any known trigger. The relevance then? Well, it behoves us to look carefully at pain before we treat. Making someone worse is not something that any podiatrist desires!
Wakefield, RSDUK Conference  (Kind permission of C. Taylor RSDUK).

The audience were consumed with an intense concentration, trying to learn more about their condition. A set of crutches on the left behind a chair, another set propped up against a folded wheel chair on the right.

**NB.** Sadly RSD(UK) is no longer functioning but other addresses can be used such as the one through the Pain Clinic at Liverpool5

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**RSD UK** - Awareness, Education and Support for those involved... www.rsd-crps.co.uk/

**RSD UK** This website is dedicated to the **RSD UK** which is now closed. ...

Changes in the delivery of services at **RSD UK** are to be made from 1st April 2007.

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**Reference**

Harris, Fallat & Schwartz 2004 JFAS vol 43, 5:296-301