Understanding complex regional pain syndrome

Abstract

Complex regional pain syndrome (CRPS), sometimes referred to as reflex sympathetic dystrophy (RSD), is a rare and poorly understood clinically diagnosed chronic pain condition that can affect any person, indiscriminate of age and sex. It is important that nurses and the wider health care team are aware of the symptoms and recommended management of this condition due to the importance of timely diagnosis and appropriate rehabilitation.

This article seeks to provide a brief overview of CRPS and provide information on how to provide appropriate nursing support for patients. Being able to understand the complexity of the condition and have knowledge of the management guidelines that exist will enable nurses to support their patients effectively.

Introduction

CRPS is a condition characterised by debilitating pain that usually affects one area of the body, most commonly a limb, but can quickly spread to other parts of the body (Thurlow and Gray, 2018). Current Royal College of Physicians (RCP) Guidelines describe CRPS as "a debilitating, painful condition in a limb, associated with sensory, motor, autonomic, skin and bone abnormalities" (Goebel *et al.*, 2018). The condition is incredibly challenging for both patients and health care practitioners (HCP); it requires a patient centered approach and an understanding of the pathophysiology and clinical presentation (Lloyd *et al.*, 2021).

The health care team that understands the pathophysiology, signs and symptoms, diagnosis, and management of CRPS ultimately provide effective care leading to a positive patient outcome. It is important that treatment for CRPS is started as soon as possible but, due to a lack of awareness and understanding, CRPS is often misdiagnosed, resulting in delayed treatment and poorer outcomes for the patient (Chang, McDonnell, and Gershwin, 2019).

What is Complex regional pain syndrome?

CRPS has historically been referred to as reflex sympathetic dystrophy (RSD), amplified musculoskeletal pain syndrome (AMPS) and causalgia with clinicians and patients still occasionally using these terms (Goebel *et al.*, 2018). It is also commonly referred to as a neuropathic pain condition due to the symptoms that occur (Pergolizzi, 2018). CRPS is complex, hence its name, and does not have any specific biomarkers, it is important that diagnostic criteria and the use of imaging is conducted to eliminate other potential diagnoses (Thomson, 2022).

In 1994 CRPS was categorised by the International Association for the Study of Pain (IASP) into two main types and a sub-type, these being CRPS types I, II and the sub-type, NOS [not otherwise specified] (Bharwani, Dirckx and Huygen, 2017). Approximately 90% of sufferers have CRPS I, with this type more frequently occurring following a minor or major tissue injury to the affected limb and it is often absent of any nerve injury. CRPS II occurs following known nerve damage or injury and CRPS-NOS is diagnosed in patients that do not formally meet the diagnostic criteria but whose symptoms cannot be explained by any other cause (Harden *et al*., 2010; Goebel et al., 2018).

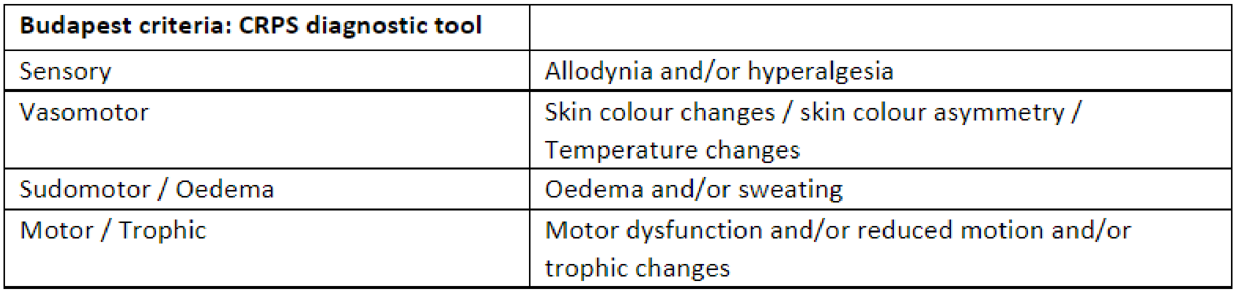
CRPS has various differential diagnoses and is identified by excluding other illnesses and ailments (Goebel *et al*., 2018). The symptoms of CRPS can mimic other conditions, and scrutiny is needed to ensure best practice guidelines are followed to enable a prompt diagnosis and initiation of early treatment (Lloyd, Dempsey, and Romero, 2021). Delay to the treatment and management of CRPS can cause secondary physical and psychological problems, associated with the lack of use of the affected limb and the consequence of living with pain (Birklein, O'Neill and Schlereth, 2015).

Research is still ongoing into the incidence of CRPS, but it is thought that it mainly affects people living in western Europe and is most common in adolescent and post-menopausal females, although males and other age groups do still receive CRPS diagnoses (Thurlow and Gray, 2018). A population study conducted in 2007 believed there to be 20-26/100,000 people that suffer from CRPS across Europe with post-menopausal females three times more likely to be affected (De Mos, 2007); no further population study has been conducted but it is thought that the number of patients affected by CRPS is now significantly more albeit still a rare condition (Goh, Chidambaram and Ma, 2017).

Signs and symptoms

It is difficult for health care practitioners to diagnose CRPS and the Budapest criteria [fig.1] was developed in 2003 to help assist in CRPS diagnostics. This criterion consists of four categories each containing signs and symptoms that are common with CRPS and has been successful in diagnosing CRPS in adults. At present there is no clinically validated tool or criteria that exists just for children and adolescents, instead, adaptations and the application of the Budapest Criteria is currently used (Lascombes and Mamie, 2017). Paediatric patients can often present differently with CRPS and therefore, a separate diagnostic criterion is required to effectively define CRPS in children and adolescents (Dickson, 2017).

Fig.1 Budapest criteria: CRPS diagnostic tool (Goebel *et al*., 2018)



Budapest criteria: CRPS diagnostic tool	
Sensory	Allodynia and/or hyperalgesia
Vasomotor	Skin colour changes / skin colour asymmetry / Temperature changes
Sudomotor / Oedema	Oedema and/or sweating
Motor / Trophic	Motor dysfunction and/or reduced motion and/or trophic changes

Adapted from Royal College of Physicians: complex regional pain syndrome in adults' guidelines

The Budapest diagnostic criteria can be viewed in detail within The Royal College of Physicians guidelines and this diagnostic criterion outlines signs and symptoms that must apply for a diagnosis of CRPS to be made (Goebel *et al*., 2018). It is important to note that patients will normally present with a variety of symptoms, the most frequent being allodynia. Other notable symptoms, such as hyperalgesia, hypersensitivity to touch and other stimuli, oedema of the affected limb with or without colour changes, skin temperature anomalies, abnormal sweating, changes to the nail or hair, loss of limb mobility and dystonia are also common (Thurlow and Gray, 2018). These symptoms can also spread to other parts of the body where there has been no history of trauma or injury (Cutts *et al*., 2021). Longer term problems such as atrophy of the muscles may also occur in which patients who can then go on to suffer from long term disability (Thomson, 2022). The patient will often be in psychological distress. CRPS is not caused *by* psychological distress, rather it develops *from* the anguish of suffering from physiological pain. Psychological distress can go on to cause more severe mental health illness and CRPS has been described by clinicians previously as the “suicide disease” (Brinkers *et al*., 2018). When using the Budapest criteria to diagnose CRPS in adults, patients must have pain which is disproportionate to precipitating event, at least one sign in two or more of the diagnostic categories, with at least one symptom in three or more of the categories. Patients also presenting with signs and symptoms from the Budapest criteria categories can also be diagnosed with CRPS if there is no other diagnosis that would explain them (Goebel *et al*., 2018).

The exact cause of CRPS is still unknown and ongoing research seeks to provide answers, however, it commonly precipitates injuries such as sprains and strains, fractures to the limb, surgical procedures, prolonged immobilisation and even minor medical procedures such as venepucture and cannulation, with an onset of symptoms normally occurring up to one month after the initial injury. It is worth noting that in approximately 9% of patients with CRPS there was no precipitating trauma at all (Kindl, 2022).

It is important to rule out other causes prior to the CRPS diagnosis being decided. This can be time consuming and often leads to frustration amongst patients and their families, especially as the guidelines dictate that timely management is essential for a positive patient outcome, and the obvious distress that comes with living in severe pain (Goebel *et al*., 2018).

Pathophysiology

It is unknown why some people develop CRPS, and why others do not, and there are contrasting theories surrounding its pathophysiology, such as autoimmune disorder, neuropathy, inflammatory malfunction, para-sympathetic nervous system dysfunction and central processing dysfunction (Mesaroli *et al*., 2021). It is agreed that CRPS is a severely disproportionate pain response to precipitating insult with nerve degeneration and dysfunction (Lascombes and Mamie, 2017). Unfortunately, CRPS can be misdiagnosed or misclassified as a psychosomatic or psychiatric disorder and whilst it can be the *cause* of some mental illness it should not be dismissed as such; it has intrinsic physiological factors which if left untreated or mistreated, can result in secondary injuries and worsen the outcome for the patient (Brinkers *et al*., 2018).

Treatment and management

The pathophysiology of CRPS is complex, with no single method of treatment being recommended. Management requires a multi-disciplinary approach largely consisting of pain relief medication, physiotherapy, occupational therapy, psychotherapy, and graded motor imagery (Lloyd, Dempsey, and Romero, 2021; Mendez-Rebolledo et al., 2017). The Royal College of Physicians (RCP) have developed UK guidelines for diagnosis, referral and management and clearly indicate the requirement of a multi-disciplinary approach (Goebel *et al*., 2018). These guidelines “Complex regional pain syndrome in adults” are the gold standard for clinicians in primary and secondary care. Initially produced in 2012 with a revision in 2018 the guidelines were originated by Dr Goebel and Dr Barker and developed by an expert panel with representation from a wide range of multi-disciplinary health sectors with The Royal College of Physicians (RCP) taking a leading role in devising the guidance.

The RCP clearly set out the four pillars of treatment [fig.2] consisting of physical rehabilitation, psychological support / intervention, pain relief and patient education / promotion of self-management; all which require input from a multi-disciplinary team.

Fig. 2, Four pillars of treatment for complex regional pain syndrome. (Adapted from Goebel *et al.*, 2018).

Four pillars of treatment
Physical and vocational rehabilitation
Psychological interventions
Pain relief
Patient education / promotion of self - management

The multi-disciplinary approach to CRPS requires careful planning to alleviate the severity of symptoms in the patient. Symptoms are debilitating and affect quality of life; therefore, a best practice approach should be applied to prevent secondary complications arising from the disease (Bruehl, 2015; Hayek and Rathmell, 2015). Misdiagnosis and delayed diagnosis of CRPS happens frequently, mainly due to the health care practitioners' (HCP) lack of knowledge about the condition. This not only causes distress to the patient but can also severely undermine the relationship they have with health care providers moving forward (Brinkers *et al*., 2018). It is important that HCP are aware of CRPS and understand the complexities of the condition, especially the effects this has on patients that require long term support.

The current RCP guidelines for treatment are based on therapeutic approaches and CRPS-specific rehabilitation techniques with therapists being competent in the application of these to people with CRPS (Goebel *et al*., 2018). The aim of treatment is to restore function in the affected limb and reduce or eradicate the pain being experienced. Physical and psychotherapies have been proven to be successful in adults and children in the restoration of limb function as well as reduced pain (González-Cantero, 2018). Hydrotherapy is also emerging as a successful treatment, especially when promoting weight bearing of the affected limb (Gutiérrez-Espinoza, Tabach-Apraiz and Oyanadel-Maldonado, 2019). These treatments combine well alongside each other and aso with psychological intervention which allow the person to develop coping mechanisms as well as identify triggers for their pain (Kessler, Yoo, and Calisoff,2020). Studies have shown standard pain analgesia to be ineffective, however, more research is needed to determine if pharmacological treatments could be effective in the acute phase of CRPS (Taylor *et al*., 2021). Most medicinal treatments used in the treatment of CRPS are based on evidence obtained from trials of medications used for various other types of pain conditions (Chang, McDonnell, and Gershwin, 2019). There are studies that support the use of initial physiotherapy treatment, with the primary goal of reducing pain and encouraging movement of the affected area. Desensitisation of the limb is often essential, alongside graded motor imagery therapy, which has been proven successful in both adults and children (Brummett and Cohen, 2013). There is currently only one randomised controlled trial that has researched psychological therapies which demonstrated certain therapies to be effective in providing behavioural strategies for patients, to enable them to cope with their physical treatments (Lloyd, Dempsey and Romero, 2021). There is some anecdotal evidence supporting the use of complimentary therapies, however, this is dependent on the patient and requires a holistic approach (Nelson, 2006).

Many patients with CRPS are concerned about receiving a lack of understanding of treatment and management and worry about their ability to access specialist services; they require additional support networks and robust facilitation of referral to these (Birklein and Schlereth, 2015). The National Service Framework (NSF) for Long Term Conditions (Department for Health, 2005) emphasises the requirement for health care providers to support patients in accessing coordinated integrated care allowing for the needs of the patient to vary over time. All health care practitioners should become knowledgeable and develop an understanding that patients with CRPS must not be immediately discharged, as their need to access specialist services will fluctuate over time.

Treatment of CRPS In Pediatrics

It is important to be aware that complex regional pain syndrome in children and young adolescents differs in its presentation from adults. However, the importance of timely diagnosis and management remains the same (Lascombes and Mamie, 2017). This can be difficult as to date there is no recognised paediatric diagnostic tool, although, the Budapest criteria is often used (Mesaroli, 2021). The main differences that present in paediatric patients are an increased prevalence in females, more commonly the lower limb/extremity being affected - with the limb being noticeably cooler in temperature, less obvious sudomotor symptoms and the presentation of influential psychological factors (Lascombes and Mamie, 2017). Diagnosis of CRPS in children relies greatly on the knowledge, experience and expertise of the health care practitioner and requires an understanding of the complexities that CRPS presents (Noel, 2021). As with adults, the treatment is multi-disciplinary with children having successful outcomes from combined physical and psychotherapies (Dickson, 2017). This multi-disciplinary approach usually involves the parents (or caregivers) and their educational setting and can be implemented in hospital (in or outpatient), in the child’s home, school or more recently over digital platforms such as Zoom or Teams (Neville *et al*., 2021). For children with more severe CRPS it is often necessary for them to be treated as an in-patient in a specialist setting, however these settings are limited with a short number of spaces and therefore, usually reserved for children that have had unsuccessful outcomes from the outpatient therapies (Dickson, 2017). The use of medications is contentious in children and can have intolerable side effects, therefore any use of medication needs to be carefully considered (Vescio, 2020). More invasive interventions, such as nerve blocks, epidurals and intravenous ketamine are available, however, there is insufficient data to provide rigorous risk versus benefit ratio (Chang, McDonnell and Gershwin, 2019). Children and adolescents present more of a challenge and the inclusion of the family is important when applying the multi-disciplinary approach (Dickson, 2017). Parents and care givers need the support of nurses when learning to understand the treatment strategies.

Nursing implications

As with any pain condition it is essential that the patients voice is heard and the level of pain they experience is acknowledged and believed (Carter, Harris and Jordan, (2021). CRPS pain is disproportionate and long lasting, causing functional disability. Nurses and other HCP often lack awareness and understanding that the pain is severe, even to the slightest touch, and should therefore reassure the patient that they are believed as well as encourage the patient to identify triggers that may exacerbate the pain. Understanding the patients' coping strategies and allowing the patient to use these is helpful and encourages independence, importantly, nurses should listen to the patient (and/or their family) and encourage this independence; this is especially important when children and adolescents are involved as often the parents/care givers are used to speaking on behalf of their child (Cox, McParland and Jordan, 2022).

Nurses should refer to The Royal College of Physicians guidelines that clearly indicate an evidence based approach to managing the care of patients with CRPS. Encouraging patients to participate in therapies can be immensely difficult and an understanding and awareness is required by the nurse to enable discussions and gentle persuasion to enable the patient to participate in rehabilitation therapies. This communication is paramount and ultimately, can have a pivotal impact on the overall patient outcome (Grieve, 2019). Nurses that understand how to support the patient need to be equipped to deal with the resistance the patient will have when being encouraged to partake in CRPS therapies, especially physical therapies.

Patient education and support

Many patients with CRPS require on-going support alongside their management by health care providers. The RCP guidelines provide information for patients comprising of charities and online sources that can be accessed. These include:

- Arthritis Research UK: http://www.arthritisresearchuk.org/arthritis-information/conditions/complex-regional-pain-syndrome.aspx
- Reflex Sympathetic Dystrophy Association (RSDSA) https://rsds.org/
- CRPS Network UK https://www.crpsnetworkuk.org/
- CRPS UK https://crps-uk.org/
- Burning nights http://www.burningnightscrps.org/

- The Royal College of Physicians https://www.rcplondon.ac.uk/guidelines-policy/complex-regional-pain-syndrome-adults

Conclusion

Complex regional pain syndrome is a rare and debilitating pain condition that is poorly understood by health care practitioners. This lack of awareness can cause misdiagnosis and delayed diagnosis, which may have severe consequences for the patient. Guidelines exist and are available to health care practitioners to support them in diagnosing, treating, and managing this condition and these should be followed closely to enable a positive outcome for the patient; failure to do this can result in secondary complications. All health care practitioners have a role in being able to treat and care for patients that suffer from pain with nurses being pivotal in this provision. To ensure that nurses can provide the correct support for patients with CRPS they must be involved in the multi-disciplinary management with the patient's voice being at the core of the relationship. CRPS management should be holistic with an integrated approach being taken and facilitation to the provision of support services should they be required.

The nurse's role is fundamental in providing support to both the patients and their family. This can only be done if there is a knowledge base and awareness of the complexities of CRPS. Patients require empathy, acknowledgement of the severity of their pain, access to timely diagnosis and holistic management in order that they obtain the best possible outcome. Nurses that understand the importance of their role in providing support and enabling participation with therapies are more likely to be able to encourage their patients and be effective in how they communicate the importance of such therapies, especially with paediatric patients. This support can enable patients to have a positive experience of health care provision, however, the opposite is true if there is a lack of awareness and understanding.

CRPS is poorly understood but with an increased awareness and a desire for nurses and other health care professionals to understand the complexities of this condition, this in turn will enable patients to receive appropriate and compassionate care without the fear of being misdiagnosed or mismanaged. It is apparent there is further research that needs to be done, therefore this increase in knowledge may be a driver to provide further research opportunities that will ultimately benefit patients.

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Appendices

Glossary of terms

Allodynia	A pain caused by a stimulus that would not normally be painful, i.e., pain provoked by a breeze or touch from a feather.
Atrophy	The wasting or degeneration of muscle tissue.
Dystonia	A neurological disorder of movement characterised by abnormal muscle contractions
Hyperalgesia	Normal pain responses are amplified and more painful than what would be expected, i.e., a pinprick causing significant pain.
Hypersensitivity	Over sensitivity to touch causing pain
Oedema	Swelling