

Turning the Nightmare of Complex Regional Pain Syndrome into a Time Of Healing, Renewal, and Hope

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Recent literature has included multiple articles about complex regional pain syndrome Type 1 (CRPS Type 1), previously known as reflex sympathetic dystrophy or complex regional pain syndrome Type 2 (CRPS Type 2), also known as causalgia (Mann, 2010; Schwarzer & Maier, 2010; van Eijs et al., 2010). If a patient is admitted to the medical-surgical unit for surgery or other interventions to control CRPS Type 1, would the nurse know the patient's special care needs? Lack of knowledge on the part of the provider may lead to a difficult hospitalization for the involved patient. However, when the nurse understands the syndrome and implements appropriate care, a hospitalization helps the patient to heal and experience renewal and hope.

Christina's Experience

Christina Montana, BSN, RN, one of the authors, has CRPS Type 1 and CRPS Type 2. Before October 2004, Christina was a Division 1 college athlete. Then her life took a dramatic turn when she underwent a bilateral fasciotomy for compartment syndrome and subsequently developed CRPS. By June 2006, Christina underwent 22 invasive procedures, including 17 paravertebral sympathetic blocks and beryllium/clonidine blocks, several blood patches into the spinal dura, tunneled epidural catheters, two neuroplasties, and insertion of a peripheral nerve stimulator, all to treat complications which arose from CRPS treatments. Complications included a

Complex regional pain syndrome is a lifelong chronic pain disorder. The medical treatment and nursing interventions, which can turn this nightmare into a time of healing, renewal, and hope, are described.

large neuroma, a herniated disc, damage of the peroneal nerve, and epidural fears accompanied by spinal headaches. In addition to these procedures, physicians prescribed multiple medications, including venous thromboembolism prophylaxis, clonidine patches (Catapres TTS[®]), morphine, gabapentin (Neurontin[®]), fentanyl patches (Duragesic[®]), bupivacaine, amitriptyline (Elavil[®]), oxycodone (Oxycontin[®]), hydromorphone (Dilaudid[®]), ketorolac (Toradol[®]), and diphenhydramine (Benadryl[®]). Christina also underwent times of bed rest or therapy, and many months of crutch walking. She received treatment in North Carolina and Ohio, often traveling between the two states. Christina and her family also spent a lot of energy coordinating her care among four doctors; at times this was frustrating, and at other times almost unbearable. For short periods during the 2 years, she was close to being pain free. However, she was in intense pain most of the time, or being treated so aggressively with medications that she was unable to function independently. A major

issue for Christina and her family was making decisions about treatment while she was in intense pain.

Christina was hospitalized approximately 12 times during this period, and she came into contact with many nursing staff. For the nurses, Christina was a short-stay surgery patient, but treatment for CRPS is far from routine. Christina's care was especially complex because she was diagnosed with both CRPS Type 1 and Type 2. An understanding of the underlying pathophysiology and current recommendations for treatment is of great help to the nurse who encounters patients with CRPS.

In spite of CRPS, Christina graduated from a nursing program, worked in critical care, and completed her BSN. She currently is studying nurse anesthesia, another demanding career choice. In this article, Christina offers evidence-based advice to medical-surgical nurses to improve their care of all patients with CRPS. Wood (2007), a physician assistant with CRPS, also has published an article to

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help physician assistants and nurse practitioners treat patients with CRPS more effectively.

Pathophysiology of Complex Regional Pain Syndrome Type 1 and Type 2

Complex regional pain syndrome Type 1 is an abnormal response of the nerves of the face or an extremity. Clinical manifestations include intense pain, autonomic dysfunction, vasomotor instability, and tissue swelling. The cause of CRPS Type 1 is frequently unknown; a diagnostic criterion for the disease is that no condition accounts for the excruciating pain and dysfunction (Stanton-Hicks, 2006). CRPS Type 1 frequently follows a stroke, trauma, neuropathy, or radiculopathic surgery, although the onset is insidious in about one-third of cases. CRPS Type 2 is associated with an identifiable nerve injury, and thus can be documented with abnormal nerve conduction studies and by surgical exploration. Most nurses are familiar with the causalgias that accompany hemiparesis after a stroke, the phantom pain that may follow an amputation, and the pain associated with long-term diabetic neuropathy. Because these pain syndromes are known to result from different pathologies, new criteria have been developed to aid in the diagnosis and treatment of CRPS (van Eijs et al., 2010).

The criteria for CRPS Type 1 and Type 2 were adopted by consensus in 1994 by the International Association for the Study of Pain (IASP) (van Eijs et al., 2010). Because the criteria were reached by consensus, they are still being validated in order to prevent over-diagnosis or under-diagnosis and increase the effectiveness of treatment (Harden, Bruehl, Stanton-Hicks, & Wilson, 2007). Mailis-Gagnon and Chaparro (2008) summarized the issues, noting “the syndrome continues to perplex, fascinate, and frustrate clinicians and researchers alike” (p. 465).

Findings by Oaklander and Fields (2009) suggested CRPS-Type 1 is a post-traumatic neuropathy associated with the distal degeneration of small-diameter peripheral axons. Axon stimulation leads to the vasomotor response, autonomic dysfunction, inflammation, and abnormal pain responses. A patient who has all the clinical manifestations of CRPS-Type 1 would exhibit the hallmark of the disease, excruciating pain (aching, burning, pricking, or shooting), as well as edema, skin blood flow changes and abnormal skin temperature (vasomotor response), and inflammation at the site.

The nurse may question the importance of differentiating between the syndromes. In fact, they are not treated the same. When one patient responds well to pain treatments and another does not respond at all, the difference may indicate incorrect diagnosis of the patient who is unresponsive to an ineffective treatment. Debate continues in the literature concerning the pathophysiology, diagnosis, and treatment of these syndromes, and tests may be used to exclude other diagnoses, rather than confirm CRPS (van Eijs et al., 2010). Not being able to find the most effective treatment is frustrating for the patient and family, and the physicians diligently trying to diagnose and treat the pain; nurses can be most helpful by empathizing with the patient and keeping an open mind. Evidence-based clinical updates from the IASP, “Coping with Pain” (Keefe, Somers, & Kothadia, 2009) and “Nonspecific Treatment Effects in Pain Management” (Jamison, 2011), support the need for nurses to be open and accepting, and listen to patients as they experience the difficult process of diagnosis and multiple treatments, many of which may be ineffective.

Treatment of Complex Regional Pain Syndrome

Given the nature of CRPS, the search continues for effective treatment regimens. The primary goal of most treatment approaches is to restore health by improving the functional ability of the patient; selected treatments thus attempt to enhance functional ability. CRPS is a multifaceted disease with multidimensional treatment, although the main focus is on pain management. Treatment frequently consists of a combination of medical therapies, including pharmacologic pain management, nerve blocks, spinal catheters, and implantable spinal cord stimulation devices, accompanied by psychological therapies and physiotherapy (occupational and physical therapy) (van Eijs et al., 2010).

The main treatment objective is to minimize pain in the affected extremity so the patient is able to exercise the limb. Managing the pain does not eliminate the disease, but it allows therapy to be performed to control the relentless symptoms (van Eijs et al., 2010). However, if pain is not managed adequately, attempting to perform any range of motion on the affected extremity is agonizingly painful and impractical.

Obtaining successful treatment in a timely manner is extremely important for the patient with CRPS. A 3-month window from the onset of symptoms to cure of the pain syndrome is typical (Stanton-Hicks, 2006). If that timeframe is passed, the disease may remain in a remission/dormant state indefinitely. However, if the 3-month window has elapsed and the pain syndrome continues, the patient may experience relentless problems. From that point, the patient may develop CRPS in any other area of the body that undergoes surgery or trauma for the rest of his or her life. In Christina’s case, the

Learn more about complex regional pain syndrome online (www.rsds.org) by accessing a comprehensive source of information for patients, their families, physicians, and nurses. The site includes up-to-date, evidence-based clinical guidelines, as well as resources for patients, families, and nurses.

pain syndrome was not cured in the 3-month window and the CRPS entered a dormant state. Although she is considered a success story in relation to the CRPS in her lower extremity, every time she has surgery she has to undergo placement of a prophylactic tunneled epidural catheter because of the inability to cure the syndrome during the appropriate timeframe. A key factor in Christina's successful treatment was her referral to Dr. Michael Stanton-Hicks in the department of pain management at the Cleveland Clinic. Dr. Stanton-Hicks and his colleagues have been responsible for a great deal of the research that has advanced the understanding and treatment of this disease. He is a regular co-author of evidence-based guidelines and research reports about the diagnosis and treatment of CRPS (Harden et al., 2007; Kapural et al., 2009; Stanton-Hicks, 2006; van Eijs et al., 2010).

Nursing Interventions for Patients with CRPS

Unfortunately, little exists in the nursing literature to help nurses care for patients who are undergoing surgery or other treatments for CRPS. There is a prime opportunity for nurses to develop evidence-based guidelines and conduct research to test nursing interventions which will aid patients with CRPS. The following discussion is derived from Christina's personal experience and other resources.

In addition to typical post-procedure and post-operative care, recommendations for nurses who care for patients with CRPS are provided in Table 1. Patients with CRPS need understanding and a special level of compassion. Not only is he or she experiencing pain from surgery, but the patient also experiences symptoms from the pain syndrome. A patient with CRPS has very unusual symptoms in the area of the dystrophy; if the nurse does not know how to assess the area appropriately, the patient could experience more pain. For example, a patient with lower leg dystro-

TABLE 1.
Nursing Interventions for Patients with CRPS

- Establish a turning schedule with the patient; use discussed interventions to decrease pain caused from tactile stimulation and prevent skin breakdown.
- Care for the surgical site, monitoring for bleeding and clinical manifestations of infection as with any postoperative patient. Monitor pain, nausea, and vomiting due to pain, and vital signs for vasomotor responses to pain. Typically the pain experienced by a patient with CRPS is severe despite the large amounts of analgesic administered. The nurse should not be judgmental if the patient's reported pain intensity remains 9 or 10 (on 0-10 intensity scale).
- Monitor sensitivity. Typically the patient with CRPS experiences severe pain in response to touch, cold, and heat. The nurse should touch the affected extremity cautiously when assessing pulses and temperature, and expect the limb to be cool to the touch and often discolored.
- Use nonpharmacologic methods to reduce pain (e.g., imagery, distraction, prayer, meditation).
- Monitor circulation and sensation of peripheral extremities. As with any postoperative patient, monitor circulation and sensation and report any problems.

Sources: Mann, 2010; Reflex Sympathetic Dystrophy Syndrome Association, (n.d.)

phy may have had surgery on the upper extremity, not the dystrophic extremity. The nurse must be able to recognize the signs and symptoms that accompany dystrophy. Because an affected patient also is likely to have a severe sensitivity to various fabrics, surfaces, and touch, he or she may not want the affected leg to be covered by a sheet and blanket because friction from the fabric causes severe pain and discomfort. Foot cradles to hold linens off the affected limbs will diminish the pain from tactile stimuli. During assessment, the nurse may find the affected limb extremely cold and therefore be inclined to cover the extremity. Extreme changes in temperature are very common and expected in the affected extremity. Heat and air conditioning in the room should be regulated according to the patient's preference. However, the patient does not feel the extremity as cold and, because of sensitivity, does not want the extremity covered. Instead, the patient may prefer to have the affected leg elevated on a pillow; when the leg is dependent and filled with blood, the patient may experience severe pain. Turning the patient in a way that puts any extra pressure, friction, or compression on the affected extremity thus could lead to an

extreme response. The patient with CRPS also is likely to have extreme swelling, with +3 - +5 pitting edema. Applying ice or heat to the edematous extremity, however, also may cause severe pain. The nurse should avoid giving injections or initiating intravenous therapy in affected extremities (Mann, 2010; Reflex Sympathetic Dystrophy Association, n.d.).

Pain management is an obvious concern with CRPS. A patient may require extremely large doses of analgesic even to begin to decrease the pain of the syndrome. The nurse might easily underestimate the pain severity, or judge or label the patient as a drug seeker. However, as with any patient, self-report of pain intensity must be believed. The nurse can be an important advocate for the patient by contacting the physician to discuss the patient's pain management needs. The nurse also should administer analgesics timely, trying to minimize the need for frequent patient requests. Routine analgesic administration contributes to the highest possible level of success in managing the patient's pain. Attempting to catch up with undertreated pain is frustrating both for the nurse and the patient (Institute for Clinical Systems Improvement, 2009; Mann, 2010).

Another important nursing intervention for a patient with CRPS is demonstration of compassion and understanding during attempts to obtain comfort for the patient. The nurse should ask the patient about past procedures and surgeries in order to understand circumstances that have contributed to the development of CRPS. For example, Christina was frustrated after undergoing aggressive but ineffective physical therapy. The syndrome forced her to leave college and forfeit an opportunity to play collegiate athletics to decrease the risk of losing a limb. Similar to Christina, a patient may be facing a 10th, 15th, or even 20th surgery, and spent the last year in confusion and constant pain despite ongoing opioid treatment (Mann, 2010; Reflex Sympathetic Dystrophy Syndrome Association, n.d.; Wood, 2007).

Taking a few minutes to sit and talk with a patient who has CRPS can be critical to treatment during a nurse's shift. The nurse should ask the patient to describe his or her pain in as much detail as possible. The patient may say, "It feels like someone poured kerosene on my leg, lit it on fire, and as it's burning...a shark is gnawing it off." Asking about the patient's experiences with CRPS is an excellent way to build a trusting nurse-patient relationship, has been shown to aid the patient in coping with pain (Jamison, 2011), and also can impact the nurse's views on the patient with chronic pain (Kautz, 2008; Mann, 2010).

The moments the nurse spends with a patient can provide hope and renewal (Kautz, 2008; Miller, 2007). Margo McCaffery, an internationally recognized pain management expert, wrote a short article more than 30 years ago entitled, "When Your Patient's Still in Pain Don't Just Do Something: Sit There" (1981). She recognized the importance of a nurse's presence with a patient in pain to provide comfort and hope for both of them. **MSN**

REFERENCES

- Harden, R.N., Bruehl, S., Stanton-Hicks, M., & Wilson, P.R. (2007). Proposed new diagnostic criteria for complex regional pain syndrome. *Pain Medicine, 8*, 326-331.
- Institute for Clinical Systems Improvement. (2009). *Health care guideline: Assessment and management of chronic pain*. Bloomington, MN: Author. Retrieved from http://www.icsi.org/guidelines_and_more/gl_os_prot/musculo-skeletal/pain_chronic_assessment_and_management_of_14399/pain_chronic_assessment_and_management_of_14400.html
- Jamison, R.N. (2011). Nonspecific treatment effects in pain medicine. *Pain Clinical Updates, 14*(2). Retrieved from <http://www.iasp-pain.org/AM/Template.cfm?Section=Home&Template=/CM/ContentDisplay.cfm&ContentID=12917>
- Kapural, L., Lokey, K., Leong, M.S., Fiekowsky, S., Stanton-Hicks, M., Sapienza-Crawford, A.J., & Webster, L.R. (2009). Intrathecal ziconotide for complex regional pain syndrome: Seven case reports. *Pain Practice, 9*(4), 296-303.
- Kautz, D.D. (2008). Inspiring hope in our rehabilitation patients, their families, and ourselves. *Rehabilitation Nursing, 33*(4), 148-153, 177.
- Keefe, F.J., Somers, T.J., & Kothadia, S.M. (2009). *Coping with pain*. *Pain Clinical Updates, 17*(5). Retrieved from <http://www.iasp-pain.org/AM/AMTemplate.cfm?Section=Home&CONTENTID=10417&TEMPLATE=/CM/ContentDisplay.cfm&SECTION=Home>
- Mailis-Gagnon, A., & Chaparro, L.S. (2008). Diagnosis and management of complex regional pain syndrome; a state-of-the-art review for the primary care physician. *Journal of Musculoskeletal Medicine, 25*, 464-469, 490.
- Mann, A. (2010). *Complex regional pain syndrome. Understanding a chronic, lifelong disorder where symptoms may be controlled but not cured*. Retrieved from <http://nursing.advanceweb.com/Continuing-Education/CE-Articles/Complex-Regional-Pain-Syndrome.aspx>
- McCaffery, M. (1981). When your patient is still in pain don't just do something: Sit there. *Nursing, 11*(6), 58-61.
- Miller, J.F. (2007). Hope: A construct central to nursing. *Nursing Forum, 42*, 12-19.
- Oaklander, A.L., & Fields, H.L. (2009). Is reflex sympathetic dystrophy/complex regional pain syndrome type I a small-fiber neuropathy? *Annals of Neurology, 65*, 629-638.
- Reflex Sympathetic Dystrophy Syndrome Association. (n.d.). *Hospital protocol RSD/CRPS patient: Handle with care!* Retrieved from <http://www.rsd.org>
- Schwarzer, A., & Maier, C. (2010). Complex regional pain syndrome. In A. Kopf & N.B. Patel (Eds.), *Guide to pain management in low-resource settings*. Retrieved from <http://www.iasp-pain.org>
- Stanton-Hicks, M. (2006). Complex regional pain syndrome: Manifestations and the role of neurostimulation in its management. *Journal of Pain and Symptom Management, 31*, S20-S24.
- van Eijs, F., Stanton-Hicks, M., Van Zundert, J., Faber, C.G., Lubenow, T.R., Mekhail, N., ... Huygen, F. (2010). Complex regional pain syndrome. *Pain Practice, 11*(1), 70-87.
- Wood, S.L. (2007). Complex regional pain syndrome. *Advance for Nurse Practitioners and Physician Assistants, 15*(9), 38.

ADDITIONAL READING

- Burton, A.W., Hassenbusch, S.J., Warneke, C., Racz, G., & Stanton-Hicks, M. (2004). Complex regional pain syndrome (CRPS): Survey of current practices. *Pain Practice, 4*, 74-83.

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