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## Reflex Sympathetic Dystrophy

Ruth L. S. Miller, MSN, RN, CNS, APRN, BC **Orthopaedic Nursing**  
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Reflex Sympathetic Dystrophy

Ruth L. S. Miller

Reflex sympathetic dystrophy, also known as complex regional pain syndrome type I, is a multisymptom syndrome usually affecting one or more extremities. It is inadequately understood and, therefore, often frustrating to treat. This article presents a case study of a 23-year career nurse who developed reflex sympathetic dystrophy of the left knee. It also reviews the rationale for reflex sympathetic dystrophy, treatment, and life-care planning for a patient with reflex sympathetic dystrophy.

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## Case Report

AH was an active 46-year-old wife, nurse of 23 years, and faculty member at a local university before injuring her left knee approximately 4 years ago while transferring a patient with the assistance of a physical therapist. At the time of injury, she felt a 'twinge,' but there was no edema or disfigurement. Within two weeks she had 'intense pain' (related as a 10 + on a 1-10 scale); she was unable to walk, put any pressure on the left leg (i.e., drive her

standard-transmission car), ascend or descend stairs, or put any type of material (sheets, blankets, clothes, etc.) on the left knee. She was getting 1-3 hours of sleep per night. A 'popping' noise was heard, followed by intense pain with flexion/extension of the knee. Vicodin and naproxen were given for the pain (which caused nausea, vomiting, and dizziness), and she was instructed to wear a leg immobilizer and referred to an orthopaedic surgeon. The x-ray and magnetic resonance imaging (MRI) were negative, even though the pain was extreme and AH continued to walk with a limp. The orthopaedic surgeon said, 'You are over 40, you're going to have aches and pains. You need to learn to deal with the pain.' Although she returned to work, the severe pain, lack of sleep, and decreased function of daily activities caused AH to seek care from a university sports medicine clinic.

During the next 10 months, AH's pain rated as an 8 to 10 on a 10-point scale, occurred with extension or flexion of the leg, and radiated from the mediofemoral condylar ridge to the thigh and left hip area. A positive Tinel's sign to palpation was present, as well as atrophy to the quadriceps. AH received a bone scan and physical therapy (for the contractures that developed) and used capsaicin cream twice a day with a knee sleeve (i.e., Ace wrap). She also received multiple trigger-point injections of steroids and/or lidocaine given to the mediofemoral condylar ridge area, which provided a decrease in pain level for 1 to 3 weeks.

Exploratory arthroscopic surgery was performed. Although no meniscal or ligament tears, fractures, or neuronal or structural damages were found, plica was removed from the left knee. One week after surgery, physical therapy was initiated due to AH's range of motion (ROM) of -20 degrees on extension to 50 degrees flexion. It took 2 months before AH could perform a full revolution when riding her stationary bike. ROM slowly yet steadily increased during the next 5 months to 0 degrees extension and 120 degrees flexion. The pain level, although not as intense, remained a 7 to 9 on a 10-point scale. Her skin on the left leg became drier than normal, shiny, and mottled, with episodes of cyanosis and areas of white patches, centering on the knee area. The left lower leg was warmer to touch when compared with the right leg. AH also had quadriceps atrophy and a contracture to the left leg.

AH was diagnosed with reflex sympathetic dystrophy (RSD) or complex regional pain syndrome type I (CRPS-I). The pain management consultant recommended physical therapy, lidocaine patches, a TENS unit, biofeedback, self-hypnosis, stress reduction, Bier blocks, trigger-point injections, spinal injections, and spinal cord stimulator as a last resort. The insurance carrier approved only the lidocaine patches, TENS unit, and Vicodin. The lidocaine patches, worn at night, and the Vicodin provided some pain relief, yet AH still only received 1 to 3 hours of sleep per night. The TENS unit brought the pain down to a 5 on a 10-point scale when awake, which permitted AH to return to a nonclinical desk job on a limited basis (she had been out of work for 5-1/2 months). After 3 months, AH's employer was unable to accommodate her restrictions of no lifting from floor, no lifting at waist level > 5 pounds, no ascending/descending stairs on a regular basis, no kneeling, no squatting, and walking limited to 10 minutes per hour. After a lengthy delay, the insurance carrier approved some of the recommended pain management, including biofeedback. Pain medications were changed to Ultram (tramadol) and Vioxx (rofecoxib). Although the Vioxx was discounted due to gastrointestinal distress, with the Ultram (25-50 mg at night), TENS unit, and biofeedback, AH's pain level is a 2 to 8 on a 1-to-10 scale, depending on the activity (i.e., sedentary vs. standing/ walking). She is able to obtain 4 to 5 hours of sleep per night consistently. (For the past 4 years, she has received, on average, 1 to 3 hours of sleep per night). Still unable to walk/hike without a significant increase in pain, AH rides, with moderate pain, a stationary bike and/or a bike in the community with her husband.

She is unable to return to clinical nursing.

After AH retrained for a sedentary position, she encountered difficulties finding employment. Potential employers expressed the inability to compensate AH according to her education level and experience. Some said 'We do not have a position for a disabled RN'. After 30 inquires and applications, AH found employment and is working 12 hours per week performing telephone patient contacts.

Since starting work, her pain has increased. However, she is able to control it to a level of 5 to 7 during work with the TENS unit and increased pain medications. She reports that she would like to work more hours but cannot due to increased exhaustion after her shifts.

## Differential Diagnosis

When a patient complains of knee pain, there are several potential diagnoses to consider. These include, but are not limited to, meniscal tears, ligament ruptures, femoral/tibial injuries (fractures, condyle injuries, etc.), muscle injuries, patella injuries, chronmalacia, plicae, tendonitis, bursitis, neuroma, iliotibial band friction syndrome, and patellofemoral syndrome. In this case scenario, AH's pain localized on the medial aspect along the mediotfemoral condyle. Before arthroscopic surgery, there was a high suspicion of a neuroma verses plicae.

### Plicae

Normal knee fetal tissue is developed by the eighth week of gestation, which consists of three synovial compartments separated by tissue. By the fourth month, this tissue is absorbed and the three compartments become one. In some people, this tissue is not absorbed. Trauma can cause this tissue to become inflamed, producing pain, a popping noise, and weakness or feeling of tightness in the knee in 15-20% of the general population ( [Fox & McGuire, 1988](#) ).

### Neuromo

A neuroma is an enlarged area or a tangle of unorganized nerve tissue, which develops after a nerve has been compressed or injured. Treatment for both neuroma and plicae calls for conservative measures-ice at first then heat, rest, aspirin or nonsteroidal antiinflammatory medications (NSAIDs), trigger-point injections, and keeping the leg extended when sitting. Antidepressants and anticonvulsants may be beneficial for a neuroma. If these measures are unsuccessful, then arthroscopic removal of the plicae or clipping of the nerve is indicated. In the current scenario, AH was treated with opioids, NSAIDs, ice, and elevation with no effect. Capsaicin, which may deplete and prevent the reaccumulation of Substance P (one of the chemicals responsible for pain transmission), was used with slight pain relief.

Trigger points, according to [Houglum \(2001\)](#) , are areas of hypersensitivity that when compressed are tender and give rise to referred autonomic stimulation. The pain is described as dull, uncomfortable, or intense. Treatment includes injection with steroids and/or lidocaine. A positive Tinel's sign (i.e., tingling sensation produced by pressing on or tapping on a damaged nerve trunk) was present in the scenario. AH had several injections, which diminished pain for 1 to 3 weeks. Because the conservative methods were not successful, arthroscopic surgery was performed.

## Knee Injuries in Women

One must not overlook the increase in knee injuries among women, especially athletes. It is believed that this increase is due to several factors: anatomy, hormones, and extrinsic factors, such as the playing surface, shoes, etc. The knee has several axes or angles used to determine any abnormalities. The Q angle (normally 15 degrees) is a measure of the angle between the quadriceps muscle and the patellar tendon. If a line were drawn from the anterior superior iliac crest to the middle of the patella and a second line from the middle of the patella to the tibial tuberosity, an angle is formed, which is termed the Q angle or quadriceps angle. The female pelvis is wider than the male pelvis, which naturally increases the female Q angle by 12 degrees more than the male Q angle ( [Austermuehle, 2001](#) ; [Houglum, 2001](#) ). A weak vastus medialis oblique muscle or a pronated or flattened foot can also increase the Q angle ( [Houglum, 2001](#) ; The Nicholas Institute of Sports Medicine and Athletic Trauma, 2000). Abnormalities in the Q angle may contribute to patellofemoral pain syndromes. The space at the bottom of the femur, which the anterior cruciate ligament (ACL) transverses (i.e., femoral notch), is narrower in females than it is in males. The increased Q angle and narrowed femoral notch are believed to be factors in ACL injuries. According to [Mirzayan \(2001\)](#) , estrogen and progesterone receptors have been identified in the ACL in a female and estrogen may affect cellular metabolism of the fibroblasts. Fibroblasts produce collagen and are vital during the reconstructive phase of wound healing.

## Reflex Sympathetic Dystrophy

After surgery, symptoms for RSD became more pronounced in AH. RSD, also known as CRPS-I, is a multisymptom syndrome usually affecting one or more extremities. RSD is inadequately understood; therefore, it is often frustrating to treat. After an injury to a nerve or soft tissue (which could be as simple as a splinter, ankle sprain, intravenous catheter insertion, back strain, etc. or as complex as a myocardial infarction, surgery, a repetitive motion disorder, an infection, etc.) the sympathetic nervous system is activated. This activation permits the body to respond appropriately to the insult by activating the inflammatory response. This stimulates the release of prostaglandins, Substance P, calcium, potassium, histamine, 5-hydroxytryptamine (5-HT), and other neurotransmitters. Normally, the sympathetic activity decreases within minutes to hours after the injury.

The hypothetical rationale for RSD/CRPS-I is that the sympathetic impulses do not shut off, triggering a constant cycle of the inflammatory response, causing the vessels to spasm, leading to continual release of neurotransmitters, and resulting in increased pain and tissue destruction. In RSD/CRPS-I, the leading precipitating event is trauma, which is often minor or spontaneous. Although both genders are affected, women have a higher incidence of RSD/CRPS-I, with the average age in the mid-30s ( [Kirkpatrick, 1999](#) ).

## Signs and Symptoms

There are three stages of severity usually associated with RSD/CRPS-I. Stage one lasts 1 to 3 months and is noted by severe and burning pain usually limited to the site of the injury, muscle cramps or spasms, edema, vasospasms that affect the color and temperature of the skin (cyanotic and cool or red and warm), and restriction in mobility. Stage 2 usually lasts 3 to 6 months. The pain becomes more diffuse and severe. Edema increases, and hair becomes coarse then scant. Nails become brittle, cracked, and grooved.

Atrophy occurs. In Stage 3, atrophy becomes irreversible and the pain becomes intractable, often involving the entire limb. Flexion tendon contractures occur, and osteoporosis may occur ( [Kirkpatrick, 1999](#) ; [National Institute of Neurological Disorders and Stroke \[NINDS\], 1998](#) ).

In this scenario, AH had several signs and symptoms of RSD/CRPS-I, although most did not present until after surgery (see [Figure 1](#) ). Pain that is disproportionate to the injury is a hallmark symptom ( [Fishman & Berger, 2000](#) ; [Kirkpatrick, 1999](#) ). The pain associated with RSD is described as burning, severe, and/or deep aching. Allodynia (tactile stimulation of the skin [i.e., wearing clothing, a light breeze, or showering], causing pain) is present. A receptor called NMDA is involved with the transmission of calcium across the postsynaptic membrane. Extended activation of this receptor and the AMPA receptor by neurotransmitters, along with a decrease in the reuptake of GABA, cause allodynia and hyperalgesia. The newer anticonvulsant medications target these ( [Nicholson, 2000](#) ).



**Figure 1.**

Signs and symptoms of reflex sympathetic dystrophy.

Tapping on the skin may cause increased pain (i.e., Tinel's sign). Sudden jolts of sharp pain may occur, especially at trigger points ( [Kirkpatrick, 1999](#) ). AH's pain was described as severe and with intermittent stabbing. Allodynia was present. Any tapping or palpation to the trigger point would increase the intensity of the pain.

Because pain was present, AH guarded the area to lessen the pain's intensity; this resulted in decreased flexion and extension of the knee. As a result, muscle atrophy and a contracture occurred. When motion is restricted, rapid changes are seen in muscle tissue, soft tissue, articular cartilage, and connective tissue. Histologic changes include a decrease in adenosine triphosphate (ATP), adenosine diphosphate (ADP), creatine phosphate (CP), creatine, glycogen, and mitochondrial production and size, which leads to a reduction in the oxidative function of a muscle. There is also a decrease in the ROM, partly due to a decrease in ground substance. Ground substance is a gel-like component of connective tissue that reduces friction between fibers. Collagen loses its strength and becomes hard and dense. Cartilage becomes thinner, the dense fibrous tissue forms around a joint, and the joint cavity is replaced by fibrofatty tissue, resulting in contractures ( [Houglum, 2001](#) ).

Normal ROM for the knee is 0 to 130 to 160 degrees, depending on the resource used ( [Houglum, 2001](#) ). To perform a full revolution on a bicycle, a ROM of 90 degrees is needed (E. Heiden, MD, personal communication December 20, 2001). It took AH 2 months of physical therapy after surgery to perform a full revolution on her bike. It is important to compare the patient's injured extremity with the noninjured extremity when determining normal ROM. AH's noninjured knee had a slight hyperextension and a flexion of 150 degrees. Her injured knee lacked 20 degrees before reaching full extension and a flexion of 50 degrees. Eighteen months after surgery (32 months after the initial injury), AH's extension was normal according to the references but less than her noninjured leg, and flexion of 120 degrees less than her noninjured leg.

Skin changes with RSD comprise warmth or coolness to skin; shinny, dry or

scaly skin; mottled/cyanosis to area; white patchy regions; redness; nails on the effected extremity become brittle, growing faster then slower; and increased sweating or chilling. Temperature changes, especially cold environments, can cause changes in skin color and pain ( [Kirkpatrick, 1999](#) ). AH became fearful the first time she noticed her left knee cyanotic with white patches. Generally, the symptoms of RSD/CRPS-I are localized to the involved extremity. Over time, they may become more diffuse.

## Treatment

The goal of the treatment for RSD/CRPS-I is to decrease pain, increase the use of the affected extremity as much as possible, and assist the patient in enjoying life, regardless of the pain ( [Figure 2](#) ). Since the inception of the Joint Commission on Accreditation of Health Care Organization (JCAHO) Standards for Pain Management in 2000, managing a patient's pain has become a high priority for nursing. The state of California passed legislation in 2000 with the intent that a patient's pain level is assessed and treated promptly and effectively as long as the pain persists (California Health and Safety Code, 2000). According to Stegman, the patient has a lifelong right to effective pain relief (2001).



**FIGURE 2.**

Treatment for reflex sympathetic dystrophy/complex regional pain syndrome type I.

In this scenario, AH had difficulty receiving treatment for pain. She was encouraged when the physicians at the sports medicine clinic were willing to persevere until proper pain management was obtained. Trigger-point injections did relieve the pain somewhat, although the intensity returned within 1 to 3 weeks. A surgical sympathectomy was attempted during the arthroscopic surgery, but the suspected nerve (infrapatellar branch of the saphenous nerve) was not located. Opiates and NSAIDs were used for 27 months. AH did not like the side effects (nausea, vomiting, somnolence, headache, etc.) and tapered herself off the medications, even though the pain was a 7 to 9 on a 1 to 10 scale.

## Transcutaneous Electrical Stimulation

A transcutaneous electrical nerve stimulator devise (TENS unit) was started 19 months after injury. Treatment using TENS is controversial. One theory states that the electrical stimulation causes an increase in the production of endorphins ( [Swanson, 1999](#) ). Other theorists believe it provides a diversion from pain, alters the neurophysiology, and blocks the pain gate or it gives a placebo effect ( [Fishman & Bergman; 2000](#) ). A TENS unit is contraindicated in patients with an implantable defibrillator/cardioverter, pacemaker, or a medication pump. Monitoring equipment such as a cardiac monitor may not operate properly when a TENS is in use ( [Sparta, no date given](#) ). The TENS unit did decrease AH's pain enough that she could get out of bed and return to work on a limited basis. She did experience skin irritation due to the TENS patches.

## Topical Medications

A lidocaine patch (Lidoderm), an adhesive dressing containing 5% lidocaine, was used by AH at night and provided some relief. Other types of medicated

patches include fentanyl and clonidine. Clonidine blocks the alpha 2 receptors of the sympathetic system. AH was offered this; however, because AH's normal blood pressure was 90/60, she believed this medication would not be appropriate because it causes hypotension. NSAIDs, anticonvulsants, and antidepressants come in topical and oral preparations. AH did use some of the preparations; however, due to the side effects she discontinued using them.

## Trigger-Point Injections

As stated, trigger-point injections of an anesthetic (lidocaine) and/or steroids are often used as a treatment for chronic pain control. According to Dr. Scott Fishman, as cited in [Barton \(2002\)](#), Botox injections are under clinical trials for a potential pain management treatment. Although the mechanism of action for botulinum toxin A is currently unknown, the data are not conclusive but strongly suggest that injections with Botox may be helpful.

## Sympathetic Blocks

Lumbar sympathetic block is sometimes used for RSD/CRPS-I of the lower extremities. The lumbar plexus, which exits the vertebral column anteriorly at L<sub>2</sub>, L<sub>3</sub>, and L<sub>4</sub>, controls the anterior aspect of the lower body. Under fluoroscopy, an anesthetic is injected into the L<sub>3</sub>-L<sub>4</sub> region. Dye is sometimes used to confirm placement. If pain relief is obtained, a series of three or more blocks may be tried. The procedure takes approximately 30 minutes, and conscious sedation is usually used. Risks include increasing pain level, damaging the spinal nerves or cord, kidney or ureter trauma, and, in extreme situations, death ([Harvard Medical College, 2002](#); [Pain Diagnostic and Treatment Center, 2002](#)).

## Radiowave Frequency and Cryoanalgesia

Radiowave frequency and cryoanalgesia are two pain treatments that are sometimes tried before a sympathectomy. During a radiowave frequency, a probe is placed in the desired tissue (often in the spinal nerves). A generator releases energy, which causes a disruption of the ions at the cellular level, causing friction. This friction produces heat. Once the temperature rises above 113 ° F (50 ° C) cellular proteins are killed and the cell membranes are fused. The size of the probe, size of the tissue, and length of time the probe is in the tissue determine how much of the nerve is ablated. The procedure normally takes approximately 10 to 15 minutes. Results vary; however, the -procedure diminishes pain for 3 to 6 months ([Ozlurk, 2001](#); [RITA Medical Systems, 2001](#)). Cryoanalgesia is the freezing of a peripheral nerve.

## Intrathecal Drug Systems

An intrathecal drug delivery system, such as a morphine pump or baclofen pump, has also been used in patients with RSD/CRPS-I. Factors that affect the pump's flow rate include body temperature, altitude, pressure at the catheter tip, and solution viscosity. It is possible for an inflammatory process to occur at the tip of the catheter, resulting in progressive neurologic deficits. An MRI, x-rays, and radiation therapy may affect the function of an intrathecal pump. Risks associated with an intrathecal drug delivery system include infections, fluid accumulation around the pump, spinal fluid leaks, spinal headaches, catheter dislodgement or fracture, battery dysfunction, damage to the spinal cord, tissue erosion, drug toxicity, or drug side effects.

A patient may use most household equipment such as microwaves, televisions, video games, stereos, and radios with intrathecal drug therapy ( [Medtronic Systems, 2002](#) ).

## Neurostimulation

Neurostimulation (also termed electrostimulation or neuromodulation) occurs when small amounts of electricity trigger a response that overpowers the pain response. Spinal cord stimulation (SCS) occurs when neuromodulation in the epidural space affects the entire central nervous system. The former term for SCS is dorsal column stimulation. This type of treatment is used for treatment of chronic trunk and/or limb pain. There are two implanted components: a power source and leads and an external controller. Some describe the electrical current as a tingling or a massaging sensation. However, these sensations are tolerable in comparison to the pain ( [Advanced Neuromodulation Systems, Inc., 2002](#) ).

A peripheral nerve stimulator (PNS) is similar to a SCS, except that its electrodes are placed outside the central nervous system targeting the peripheral nervous system. Contraindications for a SCS or PNS include patients with an implantable pacemaker or defibrillator and who are exposed to MRI, ultrasound equipment, diathermy, radiation therapy, theft detectors, security systems (metal detectors in airports), and aircraft communications systems. Adverse events include infection, bleeding, headache, hardware difficulties (fracture leads, battery dysfunction, etc.), spinal cord injury, allergic reaction to the system, paralysis, stimulation in the wrong location, failure to relieve pain, pain at the implant site, or hematoma ( [Advanced Neuromodulation Systems, Inc. 2002](#) ; [Medtronic Systems, 2002](#) ).

Spinal cord stimulation has been used successfully in some patients when other treatments have failed. After being sidelined for several years, a basketball enthusiast received the implant, and although she continued to have some pain, she was mobile again ( [Fishman & Berger, 2000](#) ). In a study by [Kemler et al. \(1999\)](#) , 23 patients with RSD/CRPS-I received an SCS. The mean pain score one month after insertion decreased from 7.9 to 4.2. Eight patients had no improvement in pain. At 32 months' postimplantation, the pain score was 5.4. Functional improvement occurred in seven patients, including some who were wheelchair bound who could walk again. Thirty nine percent (9 of 23) experienced complications.

## Acupuncture

Acupuncture is another treatment used in pain management. This procedure is not without risks. Complications include bleeding, skin irritation, poor wound healing, inflammation, pneumothorax, hemothorax, nerve irritation and damage, and even death. The challenge with RSD/CRPS-I is that any type of sympathetic stimulation may intensify pain regardless of its location (AH's dentist became frustrated when AH felt an entire dental procedure even though an anesthetic was given). Unfortunately for AH, acupuncture increased her knee pain intensity. Her sleep was also decreased to 2 to 3 hours per night due to the pain increase. The treatments were discontinued.

## Noninvasive Systemic Therapy

A newer noninvasive systemic therapy termed 'Sympathetic Therapy' uses intersecting electrical currents attached to the extremities. During the course of 2 weeks a series of 10 one-hour clinical treatments are performed on an outpatient basis. If a decrease in pain level occurs, a home device is then



used to continue the treatments. In one study of 197 patients, 33% reported total pain relief, 58% reported a mild to significant pain reduction, and 85% reported an increased in daily activities. Improvement in sleep occurred in 151 patients (77%). Contraindications include thrombosis, pacemakers, malignancy, bacterial infections, and pregnancy ( [Dynatronics Corporation, 2001](#) ). AH wants to try the treatments; however, she is awaiting insurance authorization.

## Behavioral Treatments

Behavioral treatments (sometimes referred to as cognitive behavioral therapy) are practices based on the mind and body connectiveness. Biofeedback is one behavioral method. It assists one in reaching deep relaxation and correcting the maladaptive muscle bracing. According to Dr. Daniel Rockers (as cited in [Fishman & Berger, 2000](#) ), when a patient relaxes, blood flows to the periphery and the viscera. As the periphery relaxes, muscle tension decreases, thus pain decreases. Introduced into the medical society in 1970, behavioral treatment continues to be a last resort in some healthcare professionals' and insurance companies' opinion for pain relief.

Biofeedback machines can track changes in muscle tension (electromyographic or EMG), brain waves, and electric signals across the skin (galvanic skin response or GSR), blood flow across the skin (temperature), heart rate, blood pressure, and action of some internal organs that then enable the patient to reduce the tension or sympathetic response ( [Fishman & Berger, 2000](#) ). GSR is a handheld monitor that reflects the variations in pore size and sweat gland activity, which is under sympathetic control. With increased pain (or any increase in the sympathetic system), the pores constrict, indicating tension, and produce a higher pitch on the monitor. With relaxation, the skin resistance decreases, causing a decrease in the tone. Hearing an increase or decrease in the tones can give one an awareness and assist in developing the ability to control tension and stress response. To be effective, biofeedback requires active participation on the patient's part.

Learning biofeedback is a process that must be practiced daily unlike taking a pill, which is passive and has immediate results. Sometimes there is a lag time between when the muscle relaxes and the pain decreases. This can cause one to believe the biofeedback is not working (Rocker, as cited in [Fishman & Berger, 2000](#) ). In the current scenario, AH used the GSR and the skin temperature measurement to identify the tension level, increase relaxation, thus decreasing the pain. She did practice the regimens taught in the sessions twice daily. After 2 months, AH's pain level was 2 to 4 when sitting with her knee extended and 6 to 8 when walking. She was consistently receiving 4 to 5 hours of continuous sleep per night, riding her bike six times per week, and decreasing the amount of Tramadol until she returned to work. Allodynia continued making it difficult to wear nylons, slacks, etc.

Deep breathing is a form of relaxation, which also aided AH in gaining control of her pain. When under stress, experiencing anxiety, or having pain, one usually breathes with short shallow breaths. This stimulates the sympathetic nervous system, which results in the release of epinephrine and norepinephrine. With deep breathing, the sympathetic system is quieted (Rockers, as cited in [Fishman & Berger, 2000](#) ). Visual imagining, hypnosis, and meditation are also ways a patient with RSD/CRPS-I may aid in gaining control over pain.

Sleep deprivation often accompanies pain. Fifty to seventy percent of patients experiencing pain suffer from lack of sleep. Conversely, sleep reduction potentiates' pain ( [Cohen, 1999](#) ). It is believed that increased amounts of endorphins are released if 6 hours of uninterrupted sleep are obtained ( [Meier, 2001](#) ). Patients should avoid nicotine, caffeine, and alcohol. Exercise should be performed early in the day, and the avoidance of an afternoon nap should be encouraged. Encourage the patient to address issues such as the mattress (when was the last time the mattress was flipped?), pillow, and room temperature.

In the scenario, AH had trouble sleeping due to the pain receiving 1 to 3 hours of sleep for 29 months. She now exercises in the morning and she does not consume caffeine or alcohol or use nicotine. After she started biofeedback, the psychologist recommended avoiding naps. This was extremely difficult for AH because she was fatigued from not sleeping at night. Eventually the naps decreased and nightly sleep increased. Because some pain medicines cause insomnia for some people, AH changed the time she took her pain medication (tramadol). If the pain level was > 5 on a 1-10 scale by 7 p.m., she took the bedtime dosage. Currently AH receives 4 to 5 hours sleep in a 24-hour period on a consistent basis. She recently was given a prescription for 2-mg Valium to assist with sleeping. However, AH is fearful of becoming dependent on the Valium and uses it 'only when absolutely needed.'

## Barriers to Pain Management

Donovan and Ward describe nine patient related barriers to pain management (2001) [Figure 3](#) . These barriers may prevent adequate pain treatment. The major barrier AH experienced was the side effects of the medications; therefore, she wanted to limit the amount of medications consumed. She did believe the pain could be managed at a 1 to 3 pain level. As of this date, AH has chosen not to have a lumbar sympathetic block, radiofrequency, medicine pump, or spinal cord stimulator due to the potential risks, although she does realize there is a possibility of needing these at a future date.



**FIGURE 3.**

Patient-related barriers to pain management.

## Psychological Aspect of Reflex Sympathetic Dystrophy

RSD is a lifelong disorder. The symptoms are controlled but not cured. This has a major psychological affect on not only the patient but also the family. Because RSD usually involves an extremity, loss of function of that extremity may be devastating to the patient. It is important that the patient accept this loss, which involves the grief process. This acceptance occurs gradually.

[McCaffery and Beebe \(1989\)](#) describe four stages of dealing with chronic pain. In these stages, the patient seeks a cure, hoping the pain will go away (stage 1); wonders if inappropriate or harmful treatment was received (stage 2); realizes the pain is permanent, which triggers anger, resentment, and depression (stage 3); and accepts that the pain is permanent and considers lifestyle changes (stage 4). AH sought a cure for the pain, believing that if she endured, the pain would diminish with appropriate treatment. She wondered if the delays in receiving appropriate pain management (i.e., due

to the insurance carrier and the initial orthopaedic surgeon's actions) caused further damage. She believed the surgery (i.e., clipping the nerve, removing plica if present, or making any necessary repairs) was the best treatment to ease the pain. In the postanesthesia care unit (PACU), she asked if the nerve was found and clipped. When the response was 'No,' AH felt defeated and realized that clinical nursing was no longer an option for her. Once the diagnosis of RSD/CRPS-I was made, she was once again hopeful that she could possibly return to clinical nursing or at least interact with patients and other nurses.

Once AH realized that the pain was permanent and that returning to clinical nursing was not a possibility, she began the grief process. AH became angry because the pain would be there for life and she would not be able to hike with her husband (therefore canceling planned vacations), walk for her daily exercise, work in clinical nursing, teach, drive her car (a standard transmission), shop, baby-sit, etc. She was disappointed and angered at the lack, and sometimes type, of support from friends. Comments such as: 'I had arthroscopic knee surgery and I was back to work within one week. What is wrong with you?' or 'You're not getting better because you are not thinking positive enough' or 'You are not trusting God enough' caused increased anger and resentment. One's attitude is vital in life. Yet, giving permission to experience the grief process and expressing it in a safe nonjudgmental environment is important for the patient with RSD.

AH had experience as an orthopaedic case manager. The unexplained deviation from the normal recovery rate for arthroscopic surgery was apparent and discouraging to AH. McCaffery and Beebe suggest that volunteer work has advantages of providing a support system, distracting the patient from pain, and increasing the feelings of worthiness by making a contribution to others (1989). AH offered to teach without compensation. She was told she 'could not teach now but to return when she was not disabled.' Because she was not employed and was not permitted to volunteer, AH had to relinquish some of her national nursing certifications. As the process continued, several 'friends' stopped all forms of correspondence. AH spent much of her time in solitude, which further added to her discouragement and depression. At one point, AH wondered why her doctor reversed the anesthesia after surgery and (although not indicated in RSD) why an above-the-knee amputation had not been preformed. She also wondered if she would ever stop crying. At one point, she did tell her husband to be sure the gun was not loaded. During this time, AH turned to those few friends who permitted her expression of loss and grief and supported her during the entire process. She did ride her stationary bike every day; she had a love for books, so she read an average of 45 books per year. She also kept a gratitude journal, writing one thing daily she was thankful for, and another journal in which she wrote about her thoughts, feelings, and prayers.

Dr. Harold Koenig, an expert in the link between faith and health, states 'Even when people become depressed over a difficult health problem, they recover more quickly from depression if they have a deep intrinsic religious faith' (2000, p.101). Dr. Koenig goes on to say, 'Spiritual decisions we make can make a significant difference in our mental health and quality of life' (p.172). Although AH was unable to attend religious services for several months after surgery, her belief in God and daily prayers helped as she progressed through the grief process. Reading the book *When You Can't Come Back* by cancer survivor and dominant-arm amputee [Dave Dravecky and his wife, Jan \(1992\)](#), helped AH gain hope and proper perspective. AH continues to struggle with acceptance of her disability, indicating that feelings of worthlessness often merge.

Mobility became an issue in AH's life. Certain compressive forces are placed on a joint with various activities. These forces are termed *joint reaction forces*. In activities such as walking, the patellofemoral compressive forces (PTF) equal half the body weight. Climbing stairs is approximately three times the body weight, and squatting produces a compressive force of more than seven times the body weight ( [Houglum, 2001](#) ). Prolonged sitting with the knee flexed causes extra pressures between the patella and femur ( [Austermuehle, 2001](#) ). To reduce pain, activities that increase patellofemoral forces must be restricted. Body weight also affects the PTF. [Wilmore and Costill \(1999\)](#) indicate that body mass index (BMI) has a high correlation with body fat and is a better indicator of obesity than relative weight. Although AH was petite (weight approximately 45 kg), the pain increased with walking, squatting, standing, sitting for extended periods with her knee flexed, and getting in and out of cars, especially a sport utility vehicle. She and her husband live in a single-story house with one step at the entry. AH had to dispose of all shoes that did not have flat heels. AH's activities were restricted accordingly (no hiking, no walking for daily exercise, etc.). These restrictions, although necessary, potentiated the discouragement and depression.

RSD also causes significant emotional and financial challenges for the family of the patient. A decrease in income, along with an increase in expenses for making needed adjustments, often occurs. Financial concerns about medical care, both present and future, add further burdens. This causes stress on the family relationships.

With activity limitations, the usual responsibilities of the patient (shopping, cleaning, cooking, etc.) become the family's responsibilities, which places additional stress on the family. AH felt intensely guilty because of the increased stresses placed on her husband (her husband was her only support for household responsibilities). Depending on where she was in the process, AH's income was decreased by 40% to 100%. Due to the status of the economy, AH's husband's income was at times decreased. They had to trade-in AH's car with the standard transmission for a car with an automatic transmission so AH could have transportation, which added additional financial stress. They had a detailed family budget that kept them focused on their income and spending habits. AH's husband took over the responsibilities of grocery shopping and fixing meals. Family recreational activities diminished greatly, although AH's husband's personal leisure time was respected and encouraged by AH.

## Life Care Planning

RSD/CRPS-I is a lifelong pain syndrome. Adjustments necessary for activities of daily living depend on which extremity (or extremities) is involved. Adaptive clothing may be necessary. A long-handled shoehorn, elastic shoelaces, Velcro or zippered laces, and zippered hook (or bent coat hanger) may be useful. Other items such as reacher/grabber, long-handled sponge, tub/shower bench, shower caddy to keep toiletries within easy reach, grab bars in shower/tub, shower head extension, long-handled comb/brush are options. A raised toilet seat and/or grab bars next to the toilet assist in sitting and standing by decreasing the squatting, thus easing the patellofemoral compressive forces on the knees. In the kitchen, items such as large knobs on the stove and washing machine make for easier turning. Use of lightweight dishes and cooking utensils and sliding shelves in the bathroom/kitchen, especially on the lower shelves, are valuable. Long-handled sponges, dustpans, brooms, and lightweight vacuum cleaners are important aids. A blanket support frame is necessary for one who has allodynia. Separate beds may be necessary in some cases to prevent the covers from being accidentally pulled over the extremity during sleep.

Automobiles must have doors that are easy to open and close. The seat position adjuster must be easy to manipulate for short-stature people with leg involvement to facilitate getting in and out of a vehicle. Automobile modifications such as hand brakes and hand controls are needed in some cases. Voice-activated computers and electronic equipment may be beneficial for those with dominant hand/arm involvement. Lawn care, cleaning, home maintenance, and grocery shopping services may need to be done on a contractual basis. If the patient is unable to ambulate, a wheelchair, along with home retrofitting for wheelchair accessibility, will be needed. If a manual wheelchair is needed, there is a potential for shoulder, neck, and back injuries. To prevent such injuries, an electric wheelchair may be appropriate. If the patient can no longer work in the clinical area and is reassigned to a sedentary position, as was AH, prevention of computer-associated injuries of the wrist, elbow, shoulder, neck, and back is also vital. Depending on the patient's level of function, nursing care may be appropriate. This may include an attendant care at home, relocating to an assisted living facility, or moving to a skilled nursing facility if dictated by the level of function. There may also be a need on an outpatient basis for educating about proper use of adaptive equipment, performing activities of daily living, pain management techniques, and coping strategies. Due to tightened airport security, a doctor's note on a prescription pad for the medical necessity use of the TENS unit or SCS will be needed to board an airplane. AH loves to travel, and she is intensely questioned regarding her TENS unit. She wears pants that convert into shorts to permit viewing of the TENS unit during security screening. AH also needed medical documentation for an aisle seat so she could stretch her knee during flights and wheelchair assistance in traveling to connecting flights. AH applied for and received a handicapped parking card, which decreased walking distance and enabled her to able open her car door enough so she could get in and out of her car easier. AH is currently being fitted for a customized ultra-lightweight wheelchair, has assistance with house cleaning, and has purchased a reacher/grabber to aid in decreasing the pressures on her patellofemoral joints.

In addition to adjusting to activities of daily living, a patient with RSD/CRPS-I has the challenge of meeting medical expenses. Some medicines can cost \$100 or more **per** medicine **per** month. During a lifetime, depending on the age of the patient, this can accumulate to several hundred thousand dollars just for medicine. Add to this any inpatient or outpatient treatments, supplies, or surgeries, and medical care costs can financially devastate a family.

Long-term healthcare of the patient must also be considered. Pain often leads to a sedentary lifestyle. This predisposes one to weight concerns, cardiovascular disease, osteoporosis, cancer, stroke, and diabetes. Healthy lifestyle behaviors, including proper diet, exercise, smoking cessation, and weight control must be encouraged. Lower extremity involvement restricts weight-bearing exercise such as walking. Cycling, swimming, or upper body cycling are alternatives. To assist in preventing osteoporosis, light resistance training and adequate calcium intake (1000-1500 mg/day) are essential. Biophosphates may be needed in some cases.

## Conclusion

RSD/CRPS-I is frustrating for the patient and family because of the enduring pain and the emotional, financial, and spiritual stresses it places on them. It is frustrating for medical personnel because it is difficult to diagnosis and treat. It is vital that proper pain management occurs and the patient and family are assisted in adjusting to the limitations so the patient can live a productive life.

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