

11th Annual Interprofessional Spring Symposium Case Study: “Paula / CRPS”



Paula was born in Toronto in 1987. She moved to Winnipeg, Ontario as a baby and has made her home there ever since. As a young child, Paula had many interests. She was an actor and model, starring in a number of TV commercials and on stage with the Manitoba Theatre for Young People. She volunteered for festivals around the city including Festival du Voyageur, the 1999 Pan Am Games, and the North American Indigenous Games. She received a blue stripe belt in tae kwon do and enjoyed winter sports.

In 2001, at age 13, Paula’s life changed dramatically. During an athletic event, she twisted her ankle and was left with unremitting pain. Her injury was initially diagnosed as a sprain and was treated with elevation and a tensor bandage. The pain did not abate and within days after the injury, her parents took her to an Urgent Care facility. X-rays revealed nothing broken; her ankle was wrapped and she was given a pair of crutches. The next morning she saw the pediatrician who believed Paula to be overreacting to a minor injury. He told her parents that she was “acting out” and stated to Paula directly, “You’re 13; suck it up!” Tylenol 3 (Acetaminophen with codeine) was prescribed but the pain continued. Another x-ray and a bone scan showed no fractures but the pediatrician still recommended that her leg (right leg, from knee to toes) be put into a walking cast. Paula was unable to place her foot on the ground. Additionally the angle of her toes in the cast made the use of crutches necessary. With each step Paula’s leg uncomfortably swung back and forth. The pediatrician referred Paula to a psychologist who utilized relaxation techniques that proved ineffective in controlling the pain.

Six weeks later the cast was removed yet the pain escalated. Paula now used a wheelchair and crutches to aid her mobility. Fascia, a layer of fibrous tissue around her leg muscles, was painfully twisted. The pediatrician next sent Paula to an orthopedic surgeon who put her ankle into an anterior ankle cast and referred her to a rheumatologist who ruled out arthritis. Six months later this same rheumatologist was consulted and she gave the same negative report regarding arthritis, in effect telling the surgeon to stop sending this patient to her.

Paula’s pain worsened and she was seen by a series of practitioners who were stymied by her condition. During all this time, Paula was going to physical therapy at the Children's Hospital. One therapist mentioned Reflex Sympathetic Dystrophy (RSD) as a possible diagnosis¹. Paula was referred to a new doctor who told the family that he did not believe in “newfangled” diagnoses such as RSD. Lack of definitive diagnosis and misunderstandings as to the source of the pain left Paula and her family feeling isolated and frustrated by the process. According to Paula and her mother, doctors saw her pain as a symptom, not as an aspect of a diagnosable disease. By this juncture Paula also experienced allodynia² and skin discoloration.

Paula’s daily activities and quality of life were increasingly compromised by her health condition and by the side effects of medications. She could not ride in a car without severe pain; wearing socks was too painful limiting her ability to function in the cold Canadian winter. Although encouraged to exercise to avoid atrophy in her unaffected limbs, Paula was inhibited from physical activity because of her pain.

¹ *Reflex Sympathetic Dystrophy (RSD) was the original term for what is now known as Complex Regional Pain Syndrome (CRPS), painful nerve disorders characterized by chronic severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling and extreme sensitivity to touch.*

² *Pain due to stimuli that do not ordinarily stimulate a pain response, for example, air changes or changes in temperature. Thus for example Paula felt tremendous discomfort when going up and down in an elevator.*

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One positive intervention made at this time was the prescription for shoe orthotics. Technicians fitting the orthotics were incredibly patient and exacting, shaving microscopic bits off the insoles until they were as comfortable as possible for Paula’s painful feet.

Additional referrals included a neurologist, who questioned the referral to his practice, a plastic surgeon, who then made a referral to an internist. The internist was confident he could get to the root of Paula’s problem and he ordered a series of blood tests. The results of the tests revealed a slight anemia and he recommended iron pills.

It was a sports medicine pediatrician who, taking one look at Paula’s painful, swollen, reddened leg referred her to the pain clinic. There she was formally diagnosed with Complex Regional Pain Syndrome (CRPS), a chronic disease characterized by severe pain, swelling, and changes in the skin. One of the earliest medications prescribed for Paula was nabilone (an orally active synthetic cannabinoid), which alleviated her muscle spasms. Gabapentin and amitriptyline were also prescribed and varied dosages of these medications are still part of Paula’s regimen.

Despite all she endured, Paula performed well academically. In 2005, she graduated from high school and entered the University of Winnipeg. There she became an activist for students with disabilities.

Paula’s pain however increasingly affected her physical, emotional, social and cognitive functions. Traditional pain medications, rehabilitative treatments, spinal stimulation, acupuncture, hypnotherapy, and other coping strategies did not sufficiently reduce her suffering. A regimen of ketamine and now memantine was recommended. It helped decrease Paula’s pain however unfortunate side effects included difficulties with memory and concentration, which significantly affected her coursework. Writing in particular was difficult and Paula eventually withdrew from the University.

In 2007, Paula developed skin lesions and the painful loss of toenails from both feet. The benefits of warm water pool therapy and exercise were halted due to the skin lesions and use of a public pool. In 2010, she was referred to the Mayo Clinic in Rochester, Minnesota by a dermatologist where the CRPS/RSD diagnosis was confirmed and pregabalin was prescribed. Her lesions were diagnosed as “contact dermatitis with a trigger of pain”. No other treatment suggestions were made. A neuroscientist in Australia, Dr. Lorimer Moseley, explained the lesions as trigger points or sites where chemicals associated with chronic pain are constantly being produced.

In 2010, an oral health issue arose. Eight molars, the wisdom teeth and the teeth next to them, had to be removed. These oral health conditions run in Paula’s family and are not related to her CRPS. However, an awareness of the CRPS diagnosis was critical for planning optimal pain care. The oral surgeon was fully informed not to brush up against Paula’s leg and to take care when moving her from room to room. As Paula noted: “With chronic pain like mine, even if all the big things go well, a tiny bump to my leg could throw things off badly.” The pain clinic’s anesthesiologist took time to speak to the oral surgeon and hospital anesthesiologist, so everyone was versed on problems that could arise.

“The extractions are to be held up as a good news story,” said Paula. “This episode should be seen as a shining example of how well things can work when everyone works together.”

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To this day the side effects of Paula’s medications are problematic. Her current list of daily meds includes; vitamins, calcium supplements, Metamucil, docusate, memantine, gabapentin, amitriptyline, nabilone, venlafaxine, clonidine, diclofenac, hydromorphone, erythromycin, acarbose, and granisetron. Paula continues to struggle with dry mouth but has been informed by her dentists that products to deal with this condition have side effects.

Paula is now working with a physical therapist using mirror therapy³ and a Graded Motor Imagery⁴ program. She is also working with a psychologist at the pain clinic, using thermal biofeedback. It is hoped that improved circulation might improve healing and prevent toenail loss.

Lastly, the stigma and misconceptions (public and professional) associated with Paula’s relatively unknown condition and ongoing use of pain medication present significant problems for Paula and her family.

“One of the really important things that’s needed is education and awareness, not just among the public, but among medical personnel and other groups. Pain control without debilitating side effects and without stigma would be wonderful. If my daughter's sharing of her story helps, that also would be great.” Paula’s Mother

Paula hopes to return to school and finish her degree, but for the moment, she has turned to other meaningful activities including photography and patient advocacy. She shares her experiences with those who want to learn about living with severe, unremitting pain in the hopes of helping other sufferers. A prominent step in building public awareness was Paula’s participation in the 2010 Vancouver Winter Olympics as a Torchbearer.

Drug Information Table: Source Facts and Comparisons

Generic name	Brand Name	Indications
nabilone	Cesamet	Antiemetic, helps with nausea
gabapentin	Neurontin	Epilepsy
amitriptyline		Depression
ketamine	Ketalar	Anesthesia
memantine	Namenda	Alzheimer
pregabalin	Lyrica	Neuropathic pain
venlafaxine	Effexor	Anxiety disorders, major depressive disorder
clonidine	Catapres, Nexicion	ADHD, hypertension
hydromorphone	Dilaudid, Exalgo	Pain
diclofenac	Voltaren	Analgesia, arthritis, dysmenorrhea, migraine
granisetron	Kytril	Prevention of chemotherapy and radiation induced nausea and vomiting
erythromycin		Antibacterial agent
docusate calcium		Constipation- stool softener
psyllium	Metamucil	Constipation- bulk producing fiber
acarbose	Glucobay	Slows the breakdown and absorption of sugars

³ *Mirror Therapy uses visual illusions created by a mirror for treatment of severe pain conditions.*

⁴ *Graded Motor Imagery treatments involve motor imagery that activates similar cortical networks to executed movements but does not involve actual movement of the limb.*

Learning Objectives & Competencies
11th Annual Spring Symposium April 4, 2013
8:00 a.m. - 4:00 p.m. The Forum, Biddeford

Focus: To explore the broad topic of pain, with an integrated, interprofessional* focus on patient/client safety, health, wellness.

"Patients don't care what you know until they know that you care"

LEARNING OBJECTIVES

At the conclusion of this seminar, participants will be able to:

1. Identify recent advancements that have enhanced our understanding of chronic pain across the professions.
2. Recognize potential barriers to the effective delivery of optimal health care to patients/clients who live with chronic pain.
3. Examine the central role of the patient/client and family within the interprofessional team.
4. Describe the distinctive roles and responsibilities of other professions (outside of your own), and the perspectives they bring to the health and wellness of patients and clients with chronic pain.

Examples

• Dental Hygiene • Dentistry • Exercise & Sports Science • Nurse Anesthesia • Nursing • Occupational Therapy • Pharmacy	• Physician Assistant • Physical Therapy • Physician • Psychology • Public Health • Social Work • Other
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COMPETENCIES

IPE Competencies

<i>IPEC recognizes 6 Interprofessional Competencies drawn from the US National Committee, the Centre for the Advancement of Interprofessional Education (CAIPE), and a commitment to Patient Centeredness.</i>	<u>National IPE competencies</u> ○ Values and Ethics ○ Roles and Responsibilities ○ Communication ○ Teamwork
<u>Additional CAIPE Competency</u> ○ Leadership	<u>UNE IPEC Competency</u> ○ Patient Centeredness

PAIN (IASP) Competencies

I. General - anatomy & physiology, basic sciences	II. Assessment & Psychology - measurement, cultural, gender, etc.
III. Treatment - pharm & non-pharm (including complementary therapies)	IV. Clinical States - taxonomy of pain - identify 5 axes: tissue pain (of which cancer pain is a subtype), visceral pain (including preg and labor), head / facial, nerve, including CRPS, special cases / special populations

* Interprofessional Education occurs when two or more professions learn about, from and with each other to improve collaboration and the quality of care. (CAIPE 2002)