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Restless sleep, fears and isolation

To Medical Doctors

To neuroscientists

To patients

To therapists

Sarah BOUCHARD, MSc OT, CSTP^{®6}, Sarah CHAPDELAINÉ, BSc OT, MSc(c) OT⁷, Tara L. PACKHAM, PhD, OTReg. (Ont), CSTP^{®8}, Rebekah DELLA CASA, OT, CSTP^{®9}, Claude J SPICHER⁹

There is every reason to believe it is an inflammation: a red, swollen, warmer hand or foot with boiling-burning sensations in the joint. All these appalling symptoms leaving the person exhausted following a night of restless sleep. In Budapest, after three days of deliberations, a consensus meeting of 38 experts validated the precise diagnostic criteria of this syndrome: the Complex Regional Pain Syndrome (CRPS). *NOT* incurable.

The Budapest CRPS classification quantifies the number of symptoms and clinical examination signs required to define it. This seemingly complex tool is worth using. It helps the patients recall and name their painful symptoms: "Naming is recognizing and this **feels good**" Estelle Murray (E.M.), a patient who suffered from this double disorder.

Besides the main symptoms of this ongoing pain syndrome - the boiling-burning sensations in a joint, the restless sleep, and the joint stiffness sensations - a hypersensitivity can develop when the crumpling of a newspaper or a light breeze aggravate the pain; a persistent touch aggravation. This is a second disease, in its own right, thus requires a targeted treatment.

The relief of considering hope

The Somatosensory Rehabilitation Centre of the human body was established to welcome with particular attention these patients who are tortured by the CRPS as defined in Budapest and to try to offer them a therapeutic alternative.

This syndrome is distressing, particularly due to the fluctuating joint stiffness, which is also where the burning/boiling/cold/freezing sensations are located. The sensation of stiffness in the joint is anguish-provoking since, in 98% of cases, it increases after activity as opposed to "common sense". This is how nights are interrupted by numerous wake-ups in a dark, hollow, gloomy and tacky atmosphere - Thanatos roaming around not too far - leaving people even more exhausted than the day before. Therefore, these patients should be able to benefit from

⁶ Sarah Bouchard Ergothérapeute Inc., Mercier (Qc, Canada)

e-mail : sarah.bouchard.ergo@hotmail.com **website** : sarahbouchardergo.com

⁷ School of Physical and Occupational Therapy, McGill University, Montreal (Qc, Canada)

⁸ School of Rehabilitation Sciences, McMaster University, Hamilton (ON, Canada)

⁹ Somatosensory Rehab Ctr, Freiburg, Switzerland

sleeping pills; the number of hours of sleep can be increased by a 20 to 90-minute nap during the day.

Within the rehabilitation of this syndrome, a greater importance must be given to activity prescription:

1. Restriction of the movements of the joint in which the boiling/warm/cold/freezing sensations are located;
2. Prescription of temporarily limiting touch, as much as possible, of the hypersensitive to touch territory. This must be done under the supervision of a Certified Somatosensory Therapist of Pain (CSTP®) as, although difficult to hear, activity and energetic mobilizing **nourish** the CRPS.

“The great whisper of hope comes from far away. It has gone a long way, its shoes are worn out. It rekindled fires by blowing gently, softly on embers faded by time.” E.M.

Unreasonable pain: when time loses its linearity

CRPS ($n=435$) can affect six different locations (by frequency): foot (47%), hand (35%), knee (10%), shoulder (5%), elbow (2%) and hip (1%). For most patients, this affection is paired with a persistent hypersensitivity to touch (allodynia or literally “other pain”): patients complain about pain overlapping well beyond the joint. Their complaint sounds like the pain is everywhere. As their symptoms story **jumps** in all directions, the caregivers (not always caring) may too quickly rule out the sincerity of their story, and with it the potential basis of a dialogue.

We observed that the psychopathological behaviors start to emerge as soon as the patients begin to experience too much intense pain: they become either silent or, contrariwise, logorrheic. Knowing how to behave in front of a patient who suffers from **anguishes** of fragmentation, separation, or death requires discernment. This ability to distinguish and separate consists in dealing with the situation as it is - and not as one would want it to. It should be noted that the anguish is also linked to the prognosis: the caregivers too often breaking the news - that this syndrome is incurable.

“Pain is a somatic (*soma* \equiv *body*) AND semantic (*sêma* \equiv *meaning*) experience; the two, **together, not one without the other.”**

Pain is unquestionably a gift that nobody wants. Trapped on the island of chilling pain, in the middle of the unutterable mist of the indescribable alteration, pain prevents from going towards others. After six months, seclusion becomes, gradually, one of the causes of this pain, experienced like a life sentence.

Immediacy in the searing of always

When the veil is finally torn away, it becomes the appropriate moment to interrupt the roaring routine of our scheduled therapeutic processes and to hear the unfathomable of the other’s otherness, to give meaning without consensus, because meaning remains a singular experience - and *NOT* plural.