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Suffering as a Diagnostic Indicator

Marek Rózycki and Robert Tobias

Abstract

Pain is the subjective sensation closely related to disease and treatment. Very often its diagnosis is more an expression of the diagnostician's experience than a description of the patient's actual condition. In particular, orthopedic and neurological patients who develop Complex Regional Pain Syndrome are misdiagnosed because the intensity of their sensations is disbelieved. Based on case studies, it seems appropriate to introduce an additional category of patient experience that will enable prompt recognition and appropriate treatment. The misdiagnoses under evaluation also exhibit frequent improper practitioner responses to patients' experience, ranging from open expressions of disbelief, through indifference, to helplessness and pessimism. This article presents case studies in which patients' expressions of suffering were not used to modify the treatment. Rather, medical professionals accepted the pain as normal under the circumstances and resulting from tissue damage. However, in these cases, the pain was a symptom of a new disease entity, in development since the original diagnosis. With improved patient communication and treatment procedures, such oversights can be avoided and new disease entities will be more readily diagnosable.

Keywords: pain, suffering, CRPS, diagnostic indicator

1. Introduction

Complex Regional Pain Syndrome or CRPS, is a chronic pain syndrome. Pain in medical treatment is frequently an expected symptom, and a normal manifestation of tissue trauma. However, when it reaches levels of intensity and duration beyond the expected, it may present as CRPS: it is no longer a symptom but a separate disease entity capable of making the affected person's life insufferable. CRPS may be triggered by a preceding condition. However, key to its diagnosis is the lack of any obvious tissue-related causes of pain. Its relative uncommonness has resulted in widely divergent reports by medical professionals over the years. Often, it was simply pain which eluded understanding. This has led to a host of labels used to describe it across time and in different countries. Currently, the following conditions are roughly equivalent to what is understood as CRPS:

1. Algoneurodystrophy
2. Sudeck's atrophy
3. Sudeck's disease
4. Sudeck's dystrophy (referring only to radiological features in osteoporosis)

5. Causalgia (also known as CRPS Type 2 when accompanied by nerve damage)
6. Peripheral trophoneurosis
7. Reflex sympathetic dystrophy - commonly abbreviated as RSD
8. Babinski-Froment sympathetic paralysis
9. Leriche's post-traumatic osteoporosis
10. Postinfarction sclerodactyly
11. Migratory osteolysis
12. Traumatic angiospasm; traumatic vasospasm
13. Hand-shoulder syndrome
14. Foot-hip syndrome
15. Complex Regional Pain Syndrome Type 1
16. Sudeck-Babinski-Leriche syndrome
17. Pourfour du Petit syndrome [1]

This multitude of labels confuses the diagnostic process and hampers appropriate reactions to the reported symptoms.

The earliest scholarly treatment of unaccountable pain dates from the 16th century. In the 1598 book "Les Oeuvres d'Ambroise Paré", the barber-surgeon to French kings describes Charles IX's suffering around the year 1570 who, after bloodletting to treat smallpox, complained of persistent burning pain coupled with muscle loss, contracture and inability to bend or straighten his arm [2]. We also have historic descriptions of chronic pain in wounded soldiers. Pain as separate from injury and treatment was described in *Lessons on the Principles of Surgery*, published in France in 1766 [3], where it was observed that pain may occur in areas not directly affected by earlier trauma, and affect joints and muscles without any visible skin lesion in the area affected.

In 1813, Alexander Denmark, a British surgeon who worked at the Royal Navy Hospital in Gosport, Hampshire, reported the case of a soldier who was wounded by a bullet that had passed through his upper arm. The wound itself healed quickly, however he noted in his report: "I always found him with the forearm bent and in supine position and supported by the firm grasp of the other hand. The pain was of a 'burning' nature, and so violent as to cause a continual perspiration from his face". Eventually, the arm was amputated [4], and this concluded the patient's suffering.

The American Civil War also reaped a harvest of experience in enigmatic chronic pain. Claude Bernard, Silas Weir Mitchell, George Morehouse and William Keen all described frequent intense pain in the aftermath of battle wounds in veterans and among them, reports on pain disorders from gunshot wounds and other nerve damage [5].

In the 1880s the French neurologist Jean-Martin Charcot observed dystonic movement disorders and related contractions, and hypothesized that the syndrome's genesis (described as "hysteria minor") was in unstructured changes in the nervous system which were probably biochemical or physiological in nature [6].

At the 29th Congress of the German Society of Surgeons (Deutscher Chirurgen Kongress) in 1901, Paul Sudeck delivered a paper entitled “Acute inflammatory bone atrophy”, in which he discussed changes observed in patients’ X-ray images. His examples included chronic atrophies causing exceptional disability. His influence can be seen in the use of his name in several of the labels given to this set of conditions.

During World War 1 René Leriche, an army surgeon in Strasbourg, hypothesized that the sympathetic nervous system was central in the rise of signs and symptoms of the conditions described by Sudeck. In 1917, he described a patient’s complaints of chronic pain in the arm and numbness in the armpit where he received a gunshot wound. Leriche coined the term “sympathetic neuritis” to illustrate the role of the sympathetic nervous system in neuropathic pain.

The term “reflex sympathetic dystrophy” (RSD) was introduced by James Evans around 1947 [7]. Evans described 57 patients with a syndrome characterized by intense pain and clinical symptoms which he described as “sympathetic stimulation”. The condition appeared as a consequence of fractures (21%), sprains (21%), vascular complications (19%), amputations (9%), joint or bone inflammations (5%), minor wounds (2%) and other minor injuries such as contusions (9%) and posture defects (7%). In 1973, John Bonica proposed the following three clinical stages of RSD:

- Stage 1, acute - the first three months after injury - characterized by erythema, calor, edema, significant hyperhidrosis, pain distribution unrelated to root or nerve involvement, limited range of motion and reduced muscle strength with a negative X-ray examination, but a positive scintigraphy showing hyperaccumulation;
- Stage 2, dystrophic - characterized by severe pain, skin edema, decreased hair growth, discoloration, cyanosis, persistent hyperhidrosis, muscle weakness and limited range of motion of the affected joint or joints;
- Stage 3, atrophic - characterized by lesser but nonetheless disabling pain which subsides with rest and increases with passive motion. The skin may be atrophic, thin, dry, sometimes ulcerated, cold, mottled or cyanotic in toto; possible loss of joint range of motion and muscle strength with tendon atrophy, contractures, tremors and dystonia causing a significant motor impairment of the affected limb. At this stage, the radiographic examination shows inhomogeneous regional osteoporosis (Sudeck’s atrophy).

This typology is used in some countries to this day.

The name was changed to Complex Regional Pain Syndrome in 1994 and the Orlando Conference established that CRPS could be diagnosed in presence of the following conditions [8]:

1. The presence of an initiating noxious event or a cause of immobilization.
2. Continuing pain, allodynia, or hyperalgesia with which the pain is disproportionate to any inciting event.
3. Evidence at some time of edema, changes in skin blood flow, or abnormal sudomotor activity in the region of pain.
4. This diagnosis is excluded by the existence of conditions that would otherwise account for the degree of pain and dysfunction.

Bonica's typology is currently under review. Some experts suggest a fourth stage [9], in which changes become irreversible and amputation appears the only effective method of alleviating pain in the affected limb [10]. This prospect highlights the importance of diagnosing CRPS as early as possible. Only timely treatment may save the patient. It is imperative to define the process of differentiation between pain as part of the healing process, and neuropathic pain which may lead to CRPS.

Pain is considered mainly as the subjective sensation [11] of the individual patient. This definition stipulates that the sensation is unpleasant and results from the real or hypothetical possibility of body tissue damage. The definition ignores experiences which might be perceived as positive [12]. It may seem incredible, but some people perceive pain as positive and have no negative associations with it. Although we tend to ignore this, such an attitude has firm foundations in the sphere of Western European culture: consider known martyrs and ascetics who used pain for self-improvement. In some religious practices pain is an important means towards redemption, with no negative connotations at all. Whether as "punishment" or "challenge", it may come with positive implications. Aside from spiritual overtones, medical patients often report a positive attitude towards pain when their pain is lesser than expected or when they consider alternatives worse than enduring pain.

It may therefore be accepted that people respond to pain differently and this should lead us to consider pain's applicability as a diagnostic. Patients, especially those suffering from algodystonia, motor neuron dystrophy, or CRPS [13], report pain inaccurately or too late for positive prognosis. This paper summarizes information from interviews with chronic pain sufferers in order to identify actions by medical practitioners which may have led to misunderstanding the nature of the patients' conditions.

2. Experiencing painful sensations

The effect of chronic pain on the patient is, chiefly, an altered consciousness. In chronic pain, the body is in a constant state of agitation, which is an imbalance between chemical mediators responsible for conducting and attenuating pain stimuli. As a result of chemical imbalance, patients may experience symptoms such as mood disorders, anxiety or panic attacks, or even sensory processing and memory disorders [14].

For people who have not experienced such states, the nature of the suffering may be incomprehensible. Conversely, chronic sufferers may be unaware of reporting incorrectly on their experiences.

A common practice among doctors dealing with chronic pain sufferers is to use numeric rating scales, or pain scales: patients are asked to self-assess their pain on a scale from 0 (no pain) to 10. The goal of pain scales is to give the doctor an idea of pain's intensity, but their usefulness is limited by education and experience of both the doctor and the patient. The following example will illustrate the problem: a girl aged 17 with diagnosed CRPS in the leg and clubfoot, suffering pain for a year and treated symptomatically, was admitted to hospital with abdominal pain. The patient indicated that the pain was intense and assigned it the value of 5 on the pain scale. As a result, she was classified as not requiring immediate attention and asked to wait in line. Her state rapidly deteriorated. Further investigation revealed acute appendicitis and secondary peritonitis. Had she not been a chronic pain sufferer, she would have assigned her pain the value of 9 or 10.

It is important to be aware that pain scales are relative and therefore should have limited applicability. The bottom end of the scale - "zero" - signifies no pain, however there is no equally clear definition for "ten". It could signify pain leading to unconsciousness, or pain which causes the sufferer suicidal thoughts, or is greater

than ever experienced. For some, the worst possible pain could be a toothache, for others a laceration. This lack of clear qualitative definition of pain on a pain scale leads to misinterpretations and “strategic assessments” both by diagnosticians and sufferers: patients often overestimate their pain in hope of receiving more urgent help; while medical professionals interpret patients’ estimations as exaggerated. The only incontestable feedback from using pain scales is the existence of pain.

As shown above, applying a simple pain scale may lead to incorrect diagnoses if the patient’s situation is incorrectly assessed. Orthopedic and neurologic patients suffering from CRPS as the result of medical interventions often communicate pain in the affected limb, which is interpreted by the specialists as an indicator of appropriateness of treatment and ignored. In consequence, no treatment is offered. In another example, a patient aged 16, experiencing difficulty walking, underwent a hallux valgus (bunion) operation. First her left foot was operated and after six months, in December 2018, the right foot. The post-operative wound did not heal well and in January 2019 the patient was admitted to hospital and given a course of antibiotics. Shortly afterwards she suffered an incident at school: the operated foot was struck with a door and its bones repositioned. This resulted in a further operation to reposition the bones and stabilize the foot. The patient began reporting increased pain; however, her frequent complaints became increasingly ignored by the medical staff. Both doctors and other professionals began treating the patient as hysterical and explained the pain away as natural and necessary after the operation. After several months of ineffective physiotherapy, clubfoot developed and this resulted in the CRPS diagnosis [15].

This, and other similar incidents, suggests that sufferers may not realize that when they report pain, their reports may be interpreted as imprecise and lead to inaccurate diagnoses.

Tissue damage or loss of continuity often lead to deep but reversible changes in both the peripheral and central nervous system, typically presenting as hypersensitivity and chronic pain as the body’s response to inflammation of tissue surrounding affected nerve structures. These changes accompany tissue repair processes, treatments of injuries and other conditions up until full recovery of the tissue [16]. If, however, pain exceeds the normally expected healing time, the situation changes diametrically. Pain conditions lasting more than three months necessitate the modification of the treatment process to account for chronic pain conditions [17]. Chronic pain conditions render the common pain assessment methods, used with non-sufferers, useless.

The sensation of pain in general is not as good a diagnostic as its particular form which, to differentiate it from pain, may be called suffering, and be understood as the negative sensation caused by lesions or other tissue interference, felt to be unacceptable and greater than expected. Such perceptions should be a cue for medical practitioners to suspect that the pain is not “normal” for the situation and to search for alternative or expanded diagnoses and treatments. Interviews with 35 CRPS sufferers, aged 15–45, reveal the prevalent experience of insufficient reaction by medical staff to, or disregard for, reported suffering. Since CRPS develops subsequently to a pre-existing condition, the sufferers have a unique experience of pain: they are able to compare their current sensations compounded by CRPS with past, pre-syndrome experience. Their observations have been juxtaposed in the table below. CRPS-related pain experiences are categorized as “suffering”; i.e. chronic and unacceptable in intensity. Reports of such sensations should automatically trigger a reassessment of the current diagnosis and treatment plan (**Table 1**).

The genesis of CRPS development is unidentified and the condition can only be recognized when already present. Paying attention to the above-listed symptoms may help diagnose the syndrome early enough to implement prophylactic treatment.

Interpretation of	Pre-CRPS pain experiences	Pain experiences with CRPS
Genesis	Understood, justified or even desirable, e.g. as the result of operation or treatment	Outside the patient's experience range
Intensity	Changing intensity	Persistent. No pain-free periods
Control	Can be controlled (e.g. through standard doses of drugs)	Uncontrollable (standard doses of drugs bring no relief)
Duration	Usually lasts 4–6 weeks (depending on type of treatment); changes in type, intensity, or frequency over time	Constant, with occasional periods of lesser intensity (but never entirely pain-free), lasting more than 4–6 weeks. May increase in intensity or area affected
Treatment methods	Standard procedures - even if disliked by the patient - bring about the desired improvement	Certain standard treatments (such as physical medicine and rehabilitation) may lead to worsening of the patient's state, increase pain and bring no desired rehabilitation results
Outcomes if unaddressed		May lead to depression, including thoughts of suicide
		May lead to despondency and lack of cooperation with medical professionals after experiencing increased pain following treatment
		Distrust of medical and rehabilitation practitioners
		Hyperalgesia and allodynia

Table 1.
Sufferers' reported experiences before and after developing CRPS.

Countless cases justify the necessity to identify changes in suffering and to adjust treatment appropriately. The cases listed below are all from the last two years and are representative of many other such cases.

2.1 Case: symptoms non-specific to the treated condition

Girl, 17, diagnosed with CRPS after two years of symptoms. At 15, she developed intervertebral hernia as a result of a sports injury. An orthosis was fitted and the patient was prescribed physical rehabilitation. The patient reported severe pain, which did not subside after the removal of the orthosis. Further treatment included electrostimulation, acupuncture and symptomatic treatment. At 16, the patient began reporting severe stomach symptoms. Six months later, changes characteristic of CRPS began appearing on her left leg: the leg changed coloring, hair growth increased. Bone loss occurred [18–21]. CRPS spreading to organs such as the stomach is not typical. Frequently children suffer from severe musculoskeletal pain (Amplified Musculoskeletal Pain Syndrome - AMPS), which can be interpreted as Complex Regional Pain Syndrome, Reflex Sympathetic Dystrophy, Reflex Neurovascular Dystrophy, or extensive pain, such as in fibromyalgia. CRPS was eventually diagnosed and specialist treatment commenced c. 19 months after the initial appearance of CRPS symptoms. The patient's left leg and stomach remain affected by CRPS. She is fed by a gastric (nasoduodenal - ND) tube. Leg pain causes her to periodically use crutches.

2.2 Case: identification hindered by comorbidities

Girl, 12, treated for tumor. She broke her leg in an accident at school. A typical treatment followed: the bone was set and a plaster cast was used to immobilize the

leg. From the very start, the patient reported increased pain which was interpreted as symptomatic of the tumor. After the removal of the plaster cast the limb was swollen and hypersensitive to touch. Symptomatic treatment and physical rehabilitation brought no results: the child continued to be in constant pain. After changes in the bone were discovered, CRPS was diagnosed. CRPS-specific treatment commenced over a year after the symptoms first appeared.

2.3 Case: incorrect fracture fixation

Man, 43, broke the scaphoid bone in his right hand in a motorcycle collision. The hand was immobilized with a plaster cast. The patient had a history of alcohol abuse. He did not report any discomfort resulting from an overtight cast: he ignored the growing pain and anesthetized himself with alcohol. After the removal of the cast, the pain did not subside and within three months symptoms characteristic of CRPS, such as swelling, color change and hypersensitivity, appeared. Because of his alcohol abuse, his reports of increasing persistent pain were ignored. Treatment began after the hand swelled and deformed.

2.4 Case: perioperative injuries

Appearance of additional pain signals during treatment for other conditions - mainly orthopedic operations - can be illustrated by five cases: two affected lower limbs, two affected upper limbs, and one affected a shoulder. The patients all reported severe pain and difficulty moving the affected limbs. In all cases their reports of abnormal pain were interpreted as normal pain. The patients were prescribed physical rehabilitation which brought no positive results. CRPS was not recognized until limb deformation was visible or bone loss was detected with radiographic imaging.

All this evidence suggests that there are major blind spots in diagnostic procedures where chronic pain is a factor, often preventing new disease entities from being discovered and treated. To rectify this situation, new procedures are required to complement existing procedures in situations which, currently, leave medical practitioners exposed to improvisation.

The following case illustrates issues caused by insufficient diagnostic procedures: girl, 15, was diagnosed with antero-inferior subluxation of the glenohumeral (shoulder) joint with muscle weakness of the shoulder girdle. The various treatments prescribed, such as Kirschner wire fixation, all followed existing procedures but, irrespective of the method used, the shoulder always slipped. In effect, the patient was discharged from several hospitals without positive prognosis. Doctors failed to act on the patient's reports of pain, treating it as natural and necessary under the circumstances. Over the next 120 days, the patient underwent various attempts to set the shoulder, leading to brachial plexus paralysis and gradual loss of functionality in the arm and the hand. The arm became hypersensitive and changed color. CRPS wasn't diagnosed until the detection of bone loss. Symptomatic treatment at a pain management clinic and arthrodesis improved the patient's comfort and returned relative independence to her.

Although medicine, as a study of humans and nature, appears to be closer to the humanities, its history shows it has more in common with the sciences. Physicians frequently see the human body as a mechanism. A rather complicated mechanism, but nevertheless one which allows us to specify procedures for pairing symptoms with treatments. The body is so complex that it could work if 99% of its components malfunction and, conversely, die with just 1% damage. Cause-and-effect medicine appears increasingly helpless when our cognitive apparatus identifies

new disease entities. It seems reasonable to suggest refinements to existing medical procedures. There should be a procedure for when there are no more procedures. Let us use another example, of a girl aged 15 diagnosed with antero-inferior subluxation of the glenohumeral (shoulder) joint with muscle weakness of the shoulder girdle. The various treatments prescribed, such as Kirschner wire fixation, all followed existing procedures but, irrespective of the method used, the shoulder always slipped. In effect, the patient was discharged from several hospitals without positive prognosis. Doctors failed to act on the patient's reports of pain, treating it as normal under the circumstances, because procedures which they followed did not anticipate the particular symptoms which occurred. They failed to reach beyond standard procedures to investigate the patient's condition and offer solutions; a state of affairs unfortunately common in an underfunded national health service.

3. Pain scales modification proposal

Medical professionals must be aware that a suffering patient's experiences are impossible to imagine for non-sufferers. A correctly conducted medical interview must use methods which will ensure a correct assessment of the patient's state. Quantitative pain scales should be avoided; rather, the interviewing physician should create a space for patients to freely report on their comfort levels and also to share their own observations and insights into their symptoms. The procedure should consider the following actions:

1. Establish the time period during which the patient has experienced constant or near-constant decline in comfort. A period of four weeks or more should be flagged as potential chronic suffering.
2. Elicit description of pain in the patient's own words. Patients are usually able to identify differences in their experience. The medical professional may help by suggesting adjectives describing various experiences. The following should be offered as core descriptors:
 - burning pain
 - tingling pain
 - stabbing pain
 - painful reaction to touch (e.g. by clothing)
 - hot/cold to the touch
 - pulsation
 - numbness
 - increased or diminished pain under pressure

A longer list of adjectives, appropriate to the assessed condition, ought to be available for use during the medical interview. The list should be expanded and reviewed as the dataset of performed interviews grows.

3. Ask the patient to describe any changes to their experience prior to treatment and during the course of treatment (e.g., has a new type of pain appeared? Has pain changed type or intensity?) Any change reported should be a prompt to consider whether a new condition or another disease entity has developed.
4. Pay attention to the patient's suggestions that the painkillers used are ineffective or otherwise inadequate. For example, if dosage or strength become inadequate after surgery [22].
5. If, after surgery, pain persists in the limbs for more than 2–3 months, or otherwise more than the time expected for full tissue repair from acute trauma, sprain, fracture, or surgery, consider CRPS [23].

3.1 Changes in patient communication

Correctly conducted medical interviews are key in accurate diagnoses of pain conditions. Nevertheless, medical professionals often ignore information given by patients. Feedback from c. 50 patients diagnosed with CRPS in Poland, Germany, UK and USA reveals counterproductive language used by medical professionals in response to reports of painful conditions. It is imperative that doctors be aware of such unhelpful phrases and avoid them. Their use demonstrates that patient reports are ignored and indicates a high likelihood of an incorrect diagnosis.

1. **“You do not look ill”**. Suffering, understood as unwanted, intense pain, need not be visible. Very often the professional forms a visual first impression of the patient's condition before hearing the patient's oral report. Nobody would admit disbelieving a patient, but doctors nevertheless make a “first-impressions assessment” which influences their subsequent approach and diagnosis. If the visual impression is that of a healthy individual (or healthier than the individual's own words suggest), there is a tendency to accept the more positive observation. Opposing one's own first impression may result in feelings of cognitive dissonance and incompetence.
2. **“Perhaps you should be more active”** or **“Healing must hurt”**. Both of these are symptomatic of the persistent belief in the human body's ability to self-repair. Our bodies indeed have amazing capacity for regeneration, and the patient's mental attitude - belief that they can be healed - is a factor in this capacity. However, this capacity and self-belief have their limitations and ought not to be relied on in conducting treatment. If a patient experiences increased pain as a result of following the doctors' advice, they will stop cooperating. Any further reliance on self-repair will become counter-productive.
3. **“You can learn to cope”**. It is impossible for a non-sufferer to confidently assert that the chronic sufferer - such as a CRPS sufferer - can ever learn to cope, and important to realize that treatment may be far from straightforward. Many conditions are untreatable and only subject to palliative care - and not everyone, and not under all circumstances, can learn to cope with that.
4. **“It is all in your head/you are making it up”**. Patients often report that doctors, when confronted with reports of increasing pain or requests for more painkillers, begin suspecting mental disorders. Before doctors jump to such conclusions, they ought to consider pain-causing conditions such as CRPS.

5. **“This is the end”**. As mentioned above, medical professionals may be subject to feelings of incompetence and powerlessness and this may cause unwanted reactions. Appropriate procedures are crucial to avoid situations in which a stranded professional might submit to helplessness.
6. **“You have to be more positive”**. This ties in with the belief in our ability to self-repair and reveals a patronizing attitude.
7. **“Others suffer more than you”** As outlined above, it is impossible to assess the degree of pain another person is suffering. Furthermore, chronic pain sufferers and long-term users of painkillers often cannot assess their pain levels accurately.

4. Conclusions

The old joke has it that there is no such pain that your doctor cannot take it. For severe pain sufferers, faced with inattentive medical professionals, this joke loses its humor. The widespread fear of dentists and surgeons is not caused by the nature of their work, but by the pain and discomfort their work connotes. It is vital that doctors of all specialties where chronic suffering is a possibility pay special attention to how they communicate with patients. Correct identification of the cause of pain and its mutability is key to successful treatment. It is often assumed that in certain cases pain cannot be effectively removed and that it can be a desired symptom. However, this should not extend to the assumption that it is natural and can be ignored. Pain is a key diagnostic. It offers feedback on accuracy of the chosen procedures. Take, for example, dental root canal: the pain caused by touching the exposed nerve indicates that the treatment proceeds correctly. It is a specific reaction to a specific stimulus, and it allows a specific diagnosis; diagnoses based on vague understanding of unexamined and unexplained pain have no place in proper medical procedures.

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