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Experiences of chronic pain

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ABSTRACT

The longer it lasts, the more pain permeates the existence. The individual becomes the stranger of his own life, is driven out of his person by a negative power that possesses him and that is all the more destructive the more he cannot get away from it. Many patients have to find a compromise so that pain stops being a mutilation. How can they continue to live with their pain?

Key words: Chronic pain - Identity - Biographical break - Medicine - Care

Experiences of pain

The notion of chronic pain is heterogeneous: pain may be long-term, a simple discomfort or a terrible suffering, it may appear only during certain movements or be there permanently by preventing any action; it goes along with life with its shadow or sometimes it destroys the existence itself, it is always the same or it accentuates over time, it is unpredictable. It can also affect a function, a member or the whole body, it could be present from childhood or appear slowly during the life as caused by an accident, or a surgical operation, a disease, or the ageing...

In the clinic, the assessment of pain is essentially based on the patient's statements and the intuition of the doctor or relatives. It is without evidence on the body, it does not jump to the eyes, it does not shed blood, it is without apparent evidence, except the complaint. It rarely appears with the onset of other symptoms, such as a fracture or a cancer whose evolution can be monitored. Any pain felt is enclosed in the darkness of the body and the intimacy of a consciousness, it involves a singular individual who experiences it without being able to transmit its intensity. It is always a private event, invisible to the eye, accessible only through the word of a patient on condition of trusting him^{1,2,3}.

He gets out of the ordinary social bond, releases himself from his responsibilities, he enters into the elusive sense, and his entourage no longer knows how to define and grasp him. He is no longer the person he was, nor the person he would be if he were relieved of his illness, he no longer recognizes himself, he is still in limbo, cut off from his attributes. He perceives himself mainly in terms of lack or mutilation. He then oscillates between an idealised before, loaded with all the qualities, a kind of personal golden age, and an after that marks the entrance to hell, the painful expropriation of oneself. Totally absorbed by his pain, he became the shadow of himself. The body that has become pure suffering is in radical rupture of all its old familiarities. It enters another dimension of its existence, a life now diminished. Many gestures, leisure activities become impossible. The pain's persistence leads to an escape from codes that normally capture the complexities and ambivalences of the social bond by giving them a framework. All the benchmarks are confused. If he still participates in the social bond, he no longer has all the prerogatives. The chronic painful body is a transgressive body that undermines the defenses of valid people who bear ill to confront a possible image of themselves intolerable, a broken mirror. It is hard to put yourself in its shoes. The pain of others is almost always undervalued^{1,2}.

The immersion in suffering induces an experience of solitude, the feeling of exile out of the familiar life while never having left it but with the feeling of seeing it behind a glass. The ability to intervene in the course of things is diminishing. Pain unloads the basic things of personal life by making them difficult to perform. All evidence of living is lost. Every day is an effort to be made with a multitude of painful gestures, activities that are impossible to accomplish. The individual is forced to another existence,

to relearn a life that eludes him and with which he elaborates countless compromises, invents stratagems in order to continue to existing.

A biographical break

The usual movement of meanings that feed the relationship to the world of the individual is broken, another hermeneutic regime emerges then on a painful, restrictive mode. The evidence of being oneself is broken. When pain is chronic, there are sometimes moments when it breaks all the dikes that still maintained a presence to oneself in everyday life. It was annoying, sometimes painful, altered sleep, but still “livable”, but when it destroys all the intimate defenses, it devours all existence. The individual ends up becoming the stranger of his own existence, he is driven out of his person by a negative power that has possessed him and all the more destructive that he fails to reject it. Radical otherness, absolute strangeness even if paradoxically it is lodged at the most intimate, it causes the rupture of the borders of oneself in the form of a violation. The affected individual loses control of a large part of his schedule, his marital, family, social, professional life. His hobbies are in trouble. There is a before and after pain. It damages the individual, removes him from activities that gave meaning to his life. Expressions like “*everything collapsed, the world collapsed on me*” (Cristina, 53, fibromyalgia) come back in one form or another in the mouth of most patients.

The days are all dominated by medical considerations, treatments, appointments with doctors, the comings and goings of pain. The whole system of value of the individual is altered, his existence escapes him and constrains to actions and a schedule of which he no longer has control. He stands out with his previous commitments, with the feeling of being snatched from himself and delivered to a diminished version of himself. Pain is always there, at the heart of every decision, every word, like a ghost that never ceases to haunt him.

Chronic pain is a background blade that takes everything in its path. It induces a break from the evidence of being oneself. Nothing is more like before and any memory before his installation is filled with the nostalgia of a “never again”. The old assurances, the familiarities of behaviors are put at risk. Suffering from a *tabès*, one of the long-term forms of syphilis, A. Daudet writes in *La doulou*, “In my poor carcass, hollowed out, empty by anemia, the pain resounds like the voice in a dwelling without furniture or draperies. Days, long days when there is nothing alive in me but suffering”⁴.

Caroline, 29, whose diagnosis remains uncertain for her back pain, describes her ruined life:

There is nothing you can do, neither work nor have children. It's too much. I have too much pain, with children it's not possible. I can't have a normal life, I can't play sports, I can't shop, I can't clean. That's okay. Going to restaurants is difficult, sitting for a long time. I have no life, no social life, no daily life. I have to go to bed several times a day, if I do something I have to lie down after. As I have character, at my age, we can't stand doing nothing, I still do but it hurts me very much.

Chronic pain is a projection into premature old age that leads to an unexpected experience of limitation, and even mutilation. It has an impact on the image of oneself:

When I look at the photos or when I am in front of a mirror, I do not recognize myself. I am like an old woman of some age. There are so many things I can no longer do (Roberta, 38, Algodystrophy).

To the extent that all pain is suffering, especially when it lasts, it damages the entire existence without leaving anything fallow. A thousand activities once performed without thinking become difficult: to move, go down or climb stairs, walk on the street or go for a walk, gardening, swim or drive the car, take care of your children, etc. The whole existence is upset or subject to dependence on relatives or medical assistants.

Pain both isolates and makes one dependent on others. It profoundly redefines relationships with others. Over time many couples break up, the man leaves his sick wife more easily than the other way around. It often leads to isolation, a form of exclusion, especially if the person shuts himself off in his pain and complaint, failing to reach others, still interested in them or waiting no more compassion. He feels cut off from others, away from a world he now only sees at a distance. The greater the suffering, the greater the feeling of loneliness.

Pain sometimes brings a will to regression, an abandonment to the other. In Tolstoy's account, Judge Ivan Illich feels this temptation: "At certain times, after long painful crises, as shameful as it was to admit, he wanted above all to be cared for like a sick child. He wanted to be caressed, kissed, cried by him, stroked and comforted by the children. He knew that he was a member of the Court of Appeal, that he had a greying beard and that it was therefore impossible"⁵. On the other hand, in *A Man*, the book of Philip Roth, a woman expresses her dismay and shame that she cannot now manage on her own because she suffers so much. "There's nothing shameful about this," he says. "You're wrong, you don't know what it is. Addiction, helplessness, isolation, terror – it is abominable and shameful. When you suffer, you become afraid of yourselves. This absolute alienation is terrible"⁶. If dependence is in radical contradiction with the values of an entire existence, it brings suffering to its incandescent point.

Altered sense of identity

The eruption of pain and its installation in time mark a biographical break, a break in existence between before and after, a radical redefinition of oneself. The individual has the feeling of being nothing more than the creature of his pain. "The migraine was so violent at times that she didn't recognize anyone," writes Peter Handke about her mother's end of life. She didn't want to see anything anymore. As it was buzzing in her head, you also had to speak to her very loudly. She lost all sensation in her body, banged herself on the edges, missed steps. Laughter hurt her, she only grimaced sometimes. The doctor said that a nerve was probably stuck. She was talking in a low voice,

so bad that she couldn't even moan. She bowed her head on her shoulder, but the pain continued. "I am no longer a human being"⁷. Any pain strips the individual of his old landmarks, it becomes unrecognizable in his own eyes and those of others around him. He feels too much, wearing a body in which he no longer recognizes himself and which is the place of an endless exercise of cruelty. Impossible to be oneself, impossible not to be oneself, suffering is this gap that is part of the duration.

In a way the story of the subject becomes a biography of the painful body, an endless succession of appreciation of the symptoms and their repercussions in existence. The pain chases away the old familiar sensations of being oneself and imposes its own feeling. Suddenly the body turns into another than itself, an inner enemy in the image of Gregory Samsa who awakens one day in an insect body in the news of Kafka. It hosts a torture whose subject no longer comes out since it is impossible to get rid of oneself. Experience par excellence of otherness at the heart of oneself. "The pain in my back and elsewhere makes my prison almost intolerable," writes Catherine Mansfield⁸. I manage to get up, to dress, to make good capacity to go to the restaurant and come back without being noticed: but that is literally only what I can do. For the rest, it is as if we were an insect locked in a book, so cramped that all he can do is lie flat. And even this becomes a kind of torture." For the cancer-stricken writer Jan Kott⁹, "The pain was always deaf. Omnipresent, sometimes giving me the impression of being 'beyond'. It seemed to me that I was leaving myself with this pain and going somewhere floating, like when you smoked marijuana, that you can give up for a moment and come back at the cost of some effort."

If the disease always reduces the individual to his body, the pain locks him even more into an intolerable body fragment¹. It destroys the unity of self to infinitely enlarge the painful area like an outgrowth that devours a part of existence. The pain is so fixed in a particular zone that it appears a foreign body, autonomous, dissident, a kind of outgrowth of oneself that follows its own path by destroying everything in its path. "Little by little my ribs become more painful, my limbs more bruised, my legs heavier. I perceive in my mouth a taste of ashes and my cough brings me ammonia (...). At the same time I am anxious to escape this coma which seems mortal to me and the horror of feeling bruised, torn my physical rag, my body which disgusts me. To enter into this painful, moist, unhealthy skin, seems to me an operation as horrible as for the exhausted soldier to put on wet, dirty, stinking clothes, become too stiff and too narrow, become painful to bear. It is quite possible that this is the sign of a return to life, as must be the awareness of the accident victim who discovers one after the other, all his fractures, bruises, tears"¹⁰. The painful area is a black hole that sucks all the energy, an abyss where the individual never stops falling.

Pain engages the fear of the worst when it persists day after day and becomes the only possible horizon. It is already an insistent evocation of death. But now it is in the jaws of the wolf, in the grip of the acute feeling of its caducity, of a life that finally hangs

by a thread. It must constantly reinvent itself¹. The suffering that ravages it is like an irruption of death at the heart of existence, a radical dispossession of oneself while knowing always there, witness reduced to impotence. There is no meaning to such an experience that seems to be heading for the worst. The pain in itself, writes E. Levinas, “has a paroxysm, as if something even more heartbreaking than suffering was going to happen, as if despite any lack of dimension of withdrawal that constitutes suffering, there was still free ground for an event, as if we were still to worry about something, as if we were on the eve of an event beyond that which is revealed to the end in suffering”¹¹. The unpublished and virulence of such an experience induce fear that it will worsen and ruin any possibility of continuing to live. Settled in time, it always seems to reserve an even worse surprise, it is always worsening in the mind of the painful, rather than going towards relief.

When it completely ravages the individual, it gives him the desire to put an end to suffering that exceeds the limits of tolerance and representability. In the same novel by Philip Roth, the woman, suffering intolerable pain because of her cancer, ends up being devoured by her: “Even the pictures of her grandchildren, the pictures that grandparents flood their homes, even those pictures, she should not look at them. Nothing exists but this pain”¹². She ends up committing suicide. For the person who suffers as long as his existence completely escapes him, death of course is not much for him. Dying is already done. When offered a last chance operation, R. Guérin does not hesitate and he agrees to indulge in a kind of ordeal. “How could the prospect of the operation frighten me?” he wrote shortly before his death. “I suffer too much. The life I am living right now is too painful for me to bear any regret. Whatever may happen to me – if it is the worst – I can only aspire to something else, and so I am fully focused on the future”¹³. The desire to die reflects the exhaustion of the sense resources of the individual, now overwhelmed by an inner violence that he can no longer ward off. All the stories he told himself become empty, without power against suffering.

Pain medicine?

By giving a scientific status to the disease, medicine has simultaneously depersonalized it and detached it from the patient’s experience to transform it into an organic datum, related to anonymous norms. The radical objection to naturalism and physicalism, which consider that only physical processes explain mental processes, is that organic alteration says nothing about the intensity of suffering¹. However, the same injury results in different experiences depending on the situations and the particularity of the individuals. By wanting to confine the experience in a pure consequence of biology, this dualistic approach condemns itself to the impossibility of understanding the most elementary variations of the feeling of pain and it lacks clinical sensitivity. Its probabilistic approach feeds care protocols but fails to treat or relieve many patients,

especially in the context of chronic pain. Such a medicine considers the relationship as secondary since the truth of the symptom will not come out of the mouth of the patient but only with examinations, it applies to the collection of some factual data but nothing more. The patient is reduced to the pathology highlighted by medical imaging or examinations. His words, comments on his disorders, assumptions about their origin, are perceived as obstacles or lost of time. He is referred to a secondary and passive role, his experience bringing only anecdotal elements for the doctor's judgment. Hence the rapidity of certain consultations where the patient accompanies by force his symptoms since they are inside his body but his presence is not really necessary. And, at the same time, his frustration for not being considered.

If it remains focussed to the body, medicine is only concerned with pain and not suffering, namely the lived experience of the patient. It considers disease as an object of science and discourse, configured as organic or functional signs in its medical definition (disease), it hides its status in society through health policies in particular (sickness), but especially the disease as it affects the intimate experience of the individual (illness). Perceived as a natural and universal species striking a negligible individual as host^{1,14,15,16}.

Intimate resources for relief

For many patients, the question is not always to recover but to continue to live. How to make compromises with pain so that it stops mutilating the existence? How to learn living with it? Most of the patients interviewed in my study experience moments of remission but express their feeling of always being on the edge of the razor, at the mercy of a false movement or an unexpected return of their pain.

Pain is a simultaneous somatic and symbolic tension around the injured part of the body or the thought. An inappropriate protection exhausts the subject. The more intense the suffering, the more impoverished the relationship to the world. The whole individual is constricted around his pain. His horizon of meaning is constantly barred by the organ or function from which he suffers. There is nothing more in life than this hearth of suffering that invests everything. And the more he thinks about it, the more he gives energy to his suffering in a dead end movement.

Techniques of meaning are remedies, supported by body learning. Forms of diversion, sufficiently invested, grant a royal way to focus his thoughts elsewhere and mobilize internal resources to neutralize suffering by bringing attention elsewhere: sophrology, relaxation, meditation, etc. These tools give the feeling of controlling one's experience and no longer falling prey to it. Hypnosis is a technique of the body, but above all a technique of meaning that induces an altered state of consciousness conducive to the control of physiological functions that usually escape. It comes from the customary ability to immerse in oneself, to be absorbed in a memory or a reverie by forgetting the external environment to focus strictly on the images and the affects that accompany them^{1,3}.

Initially, the subject is completely in the negative hypnosis of his pain, he removes all his attention from his environment to the benefit of a pain that he continues to aggravate. The task is to break it and open it up to other investments. The consciousness of the hypnotized subject is invested by the therapist who suggests the meanings to be experienced while temporarily freeing him from the constraints of his identity, and in particular from the over-investment of his pain. The induction aims at an escape from the investment system of the subject, and a suspension of its usual coordinates to be located in the world. Hypnosis feeds the ability to build a sense shield to cushion or eliminate pain. The individual is motionless, as if suspended in a muscular and postural atony while letting himself be carried away by his imagination but without losing control. The trance is sometimes so deep that surgical interventions are possible without pharmacological anesthesia, and chronic painful patients experience relief, and sometimes remission of their pain.

Personal resources of imagination, diversion, determination of character, contribute to the modulation of algic intensity. Chronic pain is never inevitable. Some people end up finding an analgesic solution or at least a compromise to live with their pain without being destroyed by it. They learn to tame the virulence. But this implies a refusal to pose as a victim while remaining passive. The inner resources of the subject are mobilized, his craft, his curiosity, his inventiveness, his patience, to find good interlocutors, good techniques. Chronic pain shows the radical impossibility of understanding and treating the suffering individual as a simple biology in indifference to his word and his history.

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