# Tense nerves.
# Normality, subversion and reconstruction in the experience of chronic pain.

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**Short Abstract**

*Having and being a body are proof of a perfectly accomplished embodiment and allows the subject to participate in a coherent system of meaning. If illness creeps into life, corporality undergoes an irreconcilable fracture and a different relationship between the self and society becomes necessary.*

**Long Abstract**

*When pain creeps into life, uncertainty takes the place of obviousness. Thus is developed a "knowledge of crisis" which is in tension with scientific knowledge, given reality and established system. Any crisis involves a reconstruction and therefore every uncertainty becomes a synonym for a different way to experience. In order to observe this power of uncertainty it is necessary to proceed from the point of coincidence between certainty and obviousness to pose a question: what happens when the indisputable is problematized? Starting from my fieldwork research, the aim of this paper is to frame the disorders know as* Central Sensitivity Syndromes *and specifically the* Fibromyalgia Syndrome*; through an anthropology from the body, I will investigate the creative uses of the body as a field of re-negotiation of one's "being there", and demonstrate how the disease becomes a voice which examines the experience and testifies to a crisis, a doubt, a provocative pretext to re-create oneself and the surrounding reality. Thus it is starting from the illness itself that it becomes possible to make a good "social use" of it to establish new classifications of the real originating from a transformation that is, before everything else, personal. As a consequence of the aforesaid, illness can then be considered not only physical but above all, moral.*

This paper comes out of fieldwork that gave me the opportunity to analyse the suffering experienced by fibromyalgia patients.

My research has led me to analyse the dynamics surrounding the concept of the body, understood as healthy and sick, and to reflect on several dichotomous oppositions, including norm/deviance, certainty/uncertainty and normality/crisis as they are present, lived and problematized within daily states of illness and suffering.

The link between my work and the theme of this workshop lies in the way that the analysis of the fibromyalgia syndrome has helped me to reflect on the concept of crisis as a new modality of living, a crisis that involves the destruction, re-formulation, re-organization and re-invention of the ordinary and the everyday. This crisis is first and foremost corporeal; it emerges from the body, lives in the body and uses the body as a tool for negotiating and modifying a given and established surrounding reality.

My paper is organized as follows: I seek to briefly outline some dichotomous oppositions addressing them in their relationship with the healthy body and the sick body.

This will enable me to focus on the lived experience of illness, concentrating in particular on the case of fibromyalgia syndrome, in order to outline the precise meanings attributed to crisis and uncertainty.

To speak of the everyday and its obviousness implies considering the existence and acceptance of a norm, where the norm is understood not as static but rather as something constantly re-created and shared in a specific social field. In this sense, the general meaning of certainty itself is based on the acceptance and unquestioned character of the normality of everyday life. In addition, inhabiting a certain social, historical, economic and political setting requires having the type of body that is suited to that particular form of humanity. It goes without saying that having a healthy or sick body cannot be considered neutral or meaningless; on the contrary, this must be understood beginning from the kind of setting that the specific body inhabits, moves through and makes reference to. In other words, a shared idea of how to *bodily* be and live a certain setting, contributes to determining the health or sickness of a body. This mode of being and living is generated by the boundaries that delimit a healthy or sick body, boundaries which are produced by and simultaneously reproduce a certain relationship between the individual, the body, and the surrounding reality. This is even more true in cases where the illness is considered psychological or psychosomatic, where the boundary pushes us to reflect on the relationship between norm and deviance and between inclusion and exclusion. As psychiatrist Franco Basaglia argues,

> To consider a person ill and thus exclude him or her from the world of healthy people serves to free society from its critical elements and, at the same time, reaffirms and sanctions a norm, a form of certainty, a type of normality. The therapeutic act itself thus emerges as a political and re-integrational act in that it seeks to resolve an ongoing crisis by moving back to the acceptance of that which originally provoked it. (F. Basaglia, 2010, p. 124).

What does crisis mean in this case and what relationship does it have to the body and illness? On one hand, to speak of crisis is to reference processes of medicalization and of reabsorbing experiences; as Basaglia notes, these processes aim to re-stabilize the balance and order of a given social setting. The healthy body thus understood refers to the norm and normality while the sick body references to deviance and the pathological. On the other hand, however, to speak of crisis implies evoking a lived and personal experience, an experience that attests to the existence of a rupture, an obstacle in the process of recognizing and accepting a form of normality. In that sense, if crisis is linked to uncertainty, disease can be considered as a form of dissension that is lived and embodied in the body, it originates in the body and manifests through the body. This aspect takes on a fundamental role here because it generates a new form of relationship between the subject and his social and historical reality; if the state of illness does in fact destroy the ordinary, if it brings about a constant state of uncertainty and forces subjects to coexist with a form of crisis that becomes a new way of living, it is also true that a new relationship between self and reality is continuously articulated through the corporeality itself. This is true in the case of chronic pain, where the temporal dimension leads individuals to engage in an ongoing reflection about themselves and their surroundings.

Experiences of pain and illness have a disintegrating effect on individuals in that they not only occur within the body but actually permeate all aspects of life. This is especially true in relation to patients who suffer from fibromyalgia, a chronic pain syndrome characterized by symptoms such as fatigue, asthenia, sleep disturbances, stiffness and paresthesia, myalgia, headaches, sexual problems and other symptoms, all of which vary according to factors such as stress, depression and anxiety. Epidemiologically speaking, this syndrome affects 4% of the world's population, striking mainly women aged 30-60 years old, which is a significant prevalence that has yet to be explained. Fibromyalgia is included in the ICD-10, but this classification has not led to recognition at an official level and so affected individuals cannot be sure of receiving the necessary treatments or of accessing any kind of official sick leave or disability benefits. Due to this lack of official recognition, the medical community tends to take a sceptical view of fibromyalgia as a real pathology; and yet, this scepticism can be seen as justified by the fact that patients' bodies do not display any objectively verifiable physical alterations. Fibromyalgia thus takes many years to diagnose and is often defined by exclusion: its symptomology is too complex, and there are no exams specifically targeted toward detecting it. As a result of this uncertainty, this syndrome is included among the sphere of contested illnesses that, as the term suggests, have yet to be recognized by the official medical community.

Scientific forms of knowledge tend to frame fibromyalgia as a "Functional Somatic Syndrome" or "Central Sensitivity Syndromes"; in referencing the *bio-psycho-social model*, this classification views the syndrome as a phenomenon caused by altered neuronal activity in the central nervous system which might generate dysfunctions in the transmission and perception of pain. However, there is also another element at the core of this vision: the factors that cause the emergence and continuation of the illness state are an individual's reduced capacity for tolerating physical and psychological stressors, anxiety, depressive states or anything else that, as part of the sphere of psychological distress, serves to affect the chemical process of pain sensitization. As a result, therapeutic pathways involve, on one hand, pharmacological treatments based on anti-depressives, opiates and painkillers while, on the other hand, treatments focus on the concept of patient education aimed at teaching individuals how to live with pain and to resolve their purely psychological problems through cognitive behavioral therapy.

If, as outlined above, we approach illness as something that communicates and attests to an ongoing crisis, the concept of education clearly takes on more complex nuances. As a matter of fact, education does not involve merely teaching patients how to coexist with their pain; rather, it seeks to re-educate the patient in the more specific sense of the word. Indeed, a biomedical vision medicalizes experiences by offering a purely psychological interpretation of the distress, describing it as something personal and framing the patient as an individually problematic subject who is inadequate, outside the norm and thus in need of re-integration. This vision frames the subject and his suffering as the result of somatization processes without taking into account the causes of the illness that lie rather within “the social”, in the broadest sense of the word.

In contrast, the patient suffering from fibromyalgia views his illness as something that is inextricable from the social sphere. He does not understand the disorder as a “concealed depression”: he views the suffering as a physical condition, not a mental one. Indeed, to frame fibromyalgia as the result of a mental problem means to negate the concrete existence of pain and threatens to delegitimize the real suffering. The situation is further aggravated by the lack of visible, organic dysfunction, which makes it more difficult for patients to be taken seriously: they risk being taken for malingerers. This leads patients to refuse the proposed pathways of treatment and, feeling utterly abandoned, they experience constant suffering mixed with rage and resentment, feelings that serve to further aggravate their pain.

Crisis is clearly present here and can be seen not only at the origin of the disease but also in the effect it produces. Indeed, crisis is the effect in that coexisting with fibromyalgia involves becoming isolated, being seen as crazy or depressed, watching family and social relations disintegrate, losing the job and, above all, suffering the loss of the life once lived; but crisis is also the origin of the disease: although patients reject the psychiatric interpretation of the syndrome, they tend to believe that the disease was caused by something that went wrong in their lives, a personal crisis that inevitably passed through and was experienced within the body. This belief automatically leads the patient to give a name to his own suffering; in the case of fibromyalgia syndrome, this process is fuelled by the previously-mentioned difficulty of reaching an official diagnosis.

This process is not only about naming; it also involves making sense of one’s own illness and identifying its origin and causes.

What then motivates patients to claim a diagnosis of fibromyalgia? Paradoxically, it appears that they actually come to recognize themselves as fibromyalgia sufferers by beginning from the psychiatric interpretation of the syndrome and then going on to criticize it, distance themselves from it, change it and enrich it on the basis of their own personal experiences. One’s own suffering thus becomes legitimized by stretching the biomedical interpretation in order to give it a recognized, even if only partially accepted, name. In the majority of cases I have analysed, this patients’ processes of *self-diagnosis* involved identifying bad lifestyle habits as the initial cause of the disease and focusing on relations with the outside world, rather than something purely internal, to explain the origins of their disease. In fact, the interviews I have conducted provided an account of this incorrect lifestyle as characterized by abusing and disrespecting one’s body and above all oneself, one’s personal integrity and self in relation to a given context. The patients thus described a personal crisis generated by the quality of their social and familiar relations, an excess of responsibility, the twofold roles they were called on to play especially as women, other people’s expectations, feelings of remorse and regret, the difficulty of being what they were asked to be and the exhaustion generated by the need to be “productive”. One women I had the chance to interview stated that:

> Fibromyalgia communicates a deep distress of modern times, like a cry for help and of pain that our bodies send out to the world to declare that we’ve had enough of being treated like machines, of self-control at any cost, of always keeping quiet, of always having to go it alone, to show how strong we are. The distresses of modern times are produced by the demands that society puts on every citizen of the world: the need to win out over everything and everyone, to suppress our emotions, to compete and be competitive just to avoid being left behind and seen as a loser, to walk all over others, disregarding rights and feelings. This is how we turn ourselves into mere machines, programmed by the consumer-oriented and selfish society we live in at the expense of our human dignity. This disease proves that we have limits that should not be crossed, they must be respected, we don’t necessarily have to be infallible.

The interviews showed that narrating and reconstructing the illness experiences can be seen as an attempt to work through a crisis and overcome it; to do so, however, reconstruction must necessarily begin from an act of detachment and an attack directed at the individual’s surrounding reality.

As the anthropologist Giovanni Pizza argues, to address illness in these terms is a way of putting it to a “good social use”; in the case I outline here, this approach allowed subjects to renegotiate the terms of their own existence by starting from the act of transforming themselves and the quality of their relations with the social and historical context.

It seems that illness speaks, illustrating what is best for the patients and emphasizing that misguided actions should not be repeated in the present or future; in that sense, the post-crisis understanding and reconstruction phase begins from self-diagnosis to culminate in *self-care*, a kind of care that is - as the term suggests - individual, tailor-made and personalized according to each individual's specific needs and life story. The pain remains, but in this way alone it can be diminished. Ordinariness and normality come to be recreated slowly, day by day. The body as an agent first and foremost must reclaim a space of time and this time must be managed in a way that is new and, especially, healthy; the body must meet its most critical needs and attend to its own rhythms. Patients feel driven to find a new form of balance and seek to maintain it; this requires changes in daily life in order to meet the imperative of flexibility: flexibility in commitments, responsibilities, social and familial relationships and the roles demanded of an individual. They do what they feel is right, considering what is good for them first and for others second. A new routine is thus created, a routine that is never rigid but is rather shaped by how patients feels and how their bodies are doing that day, seeking to avoid any situation that they believe might provoke physical or especially mental discomfort, any situation that involves stress, which automatically leads to an increase in pain levels. Flexibility, in this sense, becomes the only imperative to be respected and comes to characterize a new lifestyle, which is what allows them to avoid new crises.

I thus conclude by quoting from another interviewee, a women suffering from fibromyalgia who used her blog on Internet to post the 10 commandments of a fibromyalgia patient:

> 1. Thou shalt have no other thought besides your wellbeing: become selfish and never compromise your health. 2. Remember to list your virtues every week, look at yourself in the mirror and look yourself in the eye to be sure that they are true (as for your defects, try to forget them). 3. Remember at least once a week to find at least one positive side to your new life and the changes it has brought. 4. Thou shalt not think of yourself as a sick person, think rather of yourself as a person on holiday from now on. 5. Let others do all that does not actually require your presence, learn to organize their work and make them responsible for their own deeds, learn to never accept no for an answer (if you are resting, they have to take your place in dealing with bureaucratic and administrative issues, preferably without making mistakes). 6. Never compare things to the past and think not of building a future like your past: your future will be a never-ending, wonderful surprise! 7. Remember that you have been reborn and as such must "re-learn yourself" step by step (and if you spent money on psychotherapy to know your old self, consider it lost forever!) 8. Pamper yourself as much as possible aesthetically, athletically and through food, never leave yourself wanting for anything. 9. Make sure that the others also adapt to your new lifestyle. 10. Surround yourself with people who are sincere and intelligent, perceptive and understanding, sensitive and reliable; if they do not have these qualities, make them shape up or eliminate them!

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