

BODIES OF EVIDENCE:
INJUSTICES AND OPPORTUNITIES IN CENTRAL SENSITIVITY SYNDROMES

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*In this moment in our history we have something
of great import to accomplish by exercising optimism of
the intellect in order to open ways of thinking that have
for too long remained foreclosed.*

David Harvey

Abstract

Central Sensitivity Syndromes (CSS) such as Fibromyalgia (FMS), Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME) and Multiple Chemical Sensitivities (MCS) put in evidence social inequalities and injustices. Faced with this evidence, the dominant forces of society react with exclusion and various types of violence. But this dynamic also offers the opportunity to highlight key sociopolitical issues and create the conditions to increase the opportunity for critical thinking in this historic period.

Key words: Central Sensitivity Syndromes, Fibromyalgia, Chronic Fatigue Syndrome/Myalgic Encephalitis, Multiple Chemical Sensitivities, biopolitics, exclusion, injustices, mobilization.

1. Introduction

Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME), Fibromyalgia (FMS) and Multiple Chemical Sensitivities (MCS) are organic, multisystemic illnesses¹. While their symptoms differ, they have similar genetic and biochemical dysfunctions² as well as common immunological, neurological and cardiovascular problems³. Due to their similarities⁴, they are grouped as Central Sensitivity Syndromes⁵. In all three illnesses, both toxics and viruses (and possibly retroviruses) play key roles in their etiologies.

Central Sensitivity Syndromes produce extreme, unforeseeable and fluctuating symptoms, a bewildering combination of permanent flu-like symptoms, cognitive problems, dizziness and fainting, pain, extreme fatigue, digestive and hormonal problems and other incapacitating alterations⁶. Two of these three illnesses, FMS and CFS/ME, were classified by the World Health Organization⁷ with the numbers M79.9 and G93.3 respectively.

In spite of WHO's classification, those who live with these pathologies experience extreme social exclusion⁸. Without having chosen to do so, and without being aware of it, people with CSS are living evidence of much of what is wrong in our society⁹:

- economic inequalities
- exclusion of those who do not produce or consume
- gender discrimination

- linear and reductionist medical thought
- the destruction of the environment by greedy and toxic industry
- a lack of values of solidarity, and
- alienating fast-paced work.

To this unmasking, society reacts with what Appadurai calls “the anxiety of incompleteness”¹⁰. He defines this as the situation, in Western industrialized countries, where the majority of people is reminded of the uncomfortably narrow gap between their situation and the level of uncertainty and incompleteness they see that people with CSS live with. These new illnesses demonstrate that the “safety” of being healthy is fragile and that new and not so well-defined illnesses are the dark side of society¹¹.

Capitalism, in its neoliberal phase, needs to exclude groups that represent difference. Through various forms of violence, it controls all aspects of the life of a person with CSS in order to reinforce, practice and flaunt its power.

These illnesses are organic and as such should be attended to within the health care system. However, in Western countries where CSS are diagnosed and prevalent, people with CSS are most often excluded from relevant health services leaving them in a medical and legal limbo a “state of exception” as described by Agamben¹² which is not the exception but the norm.

2. Between indefinición and definition

Young adults in their most active and productive stage of life are the most frequently affected by CSS (although there are also children and adolescents with CSS). Toxics and/or viruses trigger the illnesses in the 0.5 to 5% of the general population that has a genetic predisposition¹³. The ill person is forced to live mostly housebound, lying down, in a semi-dependent or dependent state with unforeseeable moments of disability and moments of ability. This transformation into ill-health is not marked by visible signs but creates much discomfort in the person’s social milieu and in society.

Also CSS create social discomfort because they resist definition. Their multisystemic complexity is far from traditional linear medical thinking in which illnesses are attributed to only one pathogen, organ or system of the body. For those ill, indefinición, increases suffering because getting a correct diagnosis is difficult and without diagnosis there is no social recognition, no legal definition and no economic support.

On the other hand, this state of partial indefinición could provide a historically privileged moment, a time where there can exist, as Foucault says, “...a kind of contract previous to all discourse free from the restrictions of language”¹⁴. In Western medical culture, language frames illness in relation only to a well-defined diagnosis and to an “acceptable” way of living with each illness, the so-called *illness behaviours*. CSS offer a great opportunity to think in new ways about health, the body and illness experience.

Unfortunately, the creative and transformative potential of indefinición is not being made the most of by doctors, political administrations or by civil society. They are actually doing the opposite. They are determined to control people with CSS by trying to hide and ignore their limitations because they seem to bother society so much. Unintentionally, people with CSS, through their extreme symptoms, break the codes of order in society and become “an

experience without order”¹⁵.

Right now, CSS are between definition and indefinition. On one hand, the State does not want CSS to be further defined because that would require putting in place relevant health services and economic support for those who are ill. On the other hand, the State would prefer to define and restrict these illnesses. In the United Kingdom, CSS are diagnosed as psychological or psychiatric illnesses. In Spain, CSS and other emerging illnesses related to the environment (Electromagnetic Sensitivities, etc.) are being labelled “Mild Fibromyalgia”. In both the UK and Spain, defining illness becomes a tactic for reducing these illnesses to something that the medical system treats as unimportant. Governments thus do not feel they need to attend to this sector of the ill population or address the role of chemical industries and toxics in CSS.

3. Power strategies

As the prevalence of CSS becomes obvious, public administrations, political parties (and the numerous organizations that they fund and support), the medical establishment, pharmaceutical industries and chemical industries work together to develop strategies that ensure those ill do not question their power. Through numerous points of intervention, they try to carry out what Foucault calls *normalization*. “Normalization” uses doctors, psychologists, medical evaluators and administrative staff to exercise more and more precise control.

There are two important factors that confront the status quo. First, the number of people with CSS is growing, year after year. These illnesses are the tip of the iceberg due to the increase of toxics in the environment and the mutation and proliferation of viruses¹⁶. Secondly, those ill are becoming more informed thanks to new technologies and are able to organize and carry out political actions despite their health limitations.

Faced with these two factors, health administrations and other institutions change their strategies as patient activists, individually or through patient organizations, unmask them¹⁷. Their objective is to keep patients quiet and passive, forcing them to accept “norms” which are more harmful than “laws”. Laws are public knowledge while norms act in the shadows through “competent normalizers”¹⁸ such as doctors and psychologists. Norms operate in the areas human rights, behaviour, language, political involvement, etc.

These norms are inserted into the narratives of society through the media, government front groups such as the “Patients’ Universities”, by having political parties fund patient associations and through the use of chosen “patient-experts” who are paid and promoted by administrations, political parties and pharmaceutical companies¹⁹.

4. Fibro-parkings and psychiatric medication for the new refugees

Unlike other people with chronic illnesses²⁰, people with CSS experience the added suffering caused by medical and administrative negligence²¹. As the person becomes ill with FMS, CFS/ME and/or MCS, his or her biography is interrupted²². Life cannot continue as it was and the person faces enormous career, social and economic losses²³. The ill person, perplexed, finds that now he or she has a new status, similar to that of a refugee. Like refugees they have no constitutional rights such as access to relevant health services and other social

rights.

In Western industrialized countries, access to relevant specialized public health services, is almost non-existent²⁴. The few health services available, relevant or not, have waiting lists of two-to-three years²⁵, during which time the ill person gets worse²⁶. They inhabit a legal limbo with serious consequences for their work status. Public administrations have done everything possible to avoid planning health services to meaningfully address these illnesses. This approach has already backfired especially considering the increase in CSS cases²⁷. They now admit to being overwhelmed by the consequences of what they did not do in the 1980s and 90s²⁸. Still, health administrations continue to carry out various strategies to avoid attending to people who are ill with CSS. Spain offers a prime example of their negligence and abuse.

In Catalonia, Spain, the Department of Health of the Generalitat was forced to set up Specialized Hospital Outpatient Units (SHU) for FM and CFS/ME. In 2008 Resolution 203/VIII, was passed unanimously in the Catalan Parliament. The Resolution was a compromise negotiated between the three-party socialist government coalition and FMS and CFS/ME patient associations. These associations had organized a Popular Legislative Initiative (PLI) to try to get a law passed that would: ensure the establishment of SHUs, proper training for doctors on CSS, a more fair treatment by the medical evaluation board of Catalonia (ICAM), etc. To present a PLI in Catalonia (population 7 million), 50,000 signatures must be gathered in six months. These patient associations gathered 140,000 signatures in two months. Yet, the government parties made it very clear that they would bring down the PLI in Parliament unless the associations were willing to down-grade the proposed law to a resolution which has less clout. Faced with the hard decision of having the budding CSS movement live a possible defeat, the patient leaders made the hard decision to negotiate Resolution 203/VIII.

After two years of not implementing the Resolution, but with continued pressure from patients associations, the Catalan Department of Health has found another way to avoid attending to the 5% of the population who live with CSS²⁹: the “fibro-parkings”. Instead of attending to CSS patients correctly as the Resolution spells out through internal medicine, paediatrics, rheumatology and cardiology specialists, these new SHUs have become a sham coordinated mostly by rheumatologists who are close to the party in power that runs the Department of Health³⁰ and, many of whom are collaborating with the pharmaceutical company, Pfizer, that makes Lyrica³¹, the neuroleptic medication they give patients in SHUs, even though the European Medication Evaluation Agency has banned it for use in Fibromyalgia³².

When the ill person arrives at one of these SHUs, regardless of whether they have CFS/ME, MCS or FMS, they are diagnosed with Fibromyalgia, making the prevalence of this illness in Spain seem the highest in the world with 5 to 14%^{33 34} of the general population diagnosed as having it. This is very far from the 2.4% established by the American Rheumatology Association³⁵ and has already been pointed out by some leading Spanish doctors³⁶. This Fibromyalgia diagnosis is done with no testing³⁷ and no functional assessment to see if it is a mild case or a severe one. After being diagnosed, the patient is

prescribed an antidepressant, a neuroleptic (Lyrica) and is “parked” in an “educational group” or in Cognitive Behavioural Therapy.

Lack of proper medical services for people with CSS is forcing them to look for relevant medical care in the private sector. This adds to social inequality and makes socio-economic class a major issue in CSS. Patients who turn to private health services pay an average of 6,000 Euros a year for testing and treatment³⁸.

Most doctors in developed countries, until recently, were not familiar with Fibromyalgia, CFS/ME nor MCS³⁹. But now, especially in the case of FMS and CFS/ME (MCS are still largely unknown), doctors say that they “don’t believe in them”⁴⁰, as though organic illnesses were an opinion or a belief. They make fun of patients with these illnesses saying that they are “fakers”⁴¹. In reality, doctors neither “believe” in them nor do they know how to treat them properly⁴². The few doctors who are diagnosing FMS and CFS/ME do so without the proper testing procedure established by the Canadian Criteria^{43 44}, recognized throughout the world as the tool for diagnosing these pathologies properly⁴⁵. When these doctors diagnose, they do so using general symptom reporting and proceed to prescribe antidepressants and anti-inflammatory medication, both of which are harmful to the health of people with CSS because they damage the already faulty mitochondrial, immunological and biochemical processes⁴⁶.

When a person is diagnosed with a CSS, he or she is pressured in a coercive manner⁴⁷ to participate in “treatments” that are not really treatments. Cognitive Behavioural Therapy (CBT) and Gradual Exercise Therapy (GET) are routinely prescribed but have been demonstrated to be inefficient and even harmful for people with CSS^{48 49 50}.

At the same time, most doctors do not know how to diagnose the overlapping that is present between these three illnesses in 70% of cases⁵¹. These illnesses are “micropathologies” which means that the damage is inside the cells or on the cell membrane⁵² and regular blood tests do not detect such damage.

This lack of knowledge on the doctor’s part and their abusive attitude towards people with CSS⁵³ drive these patients onto a *medical pilgrimage* to find a competent doctor who might have some knowledge of CSS.

After the *medical pilgrimage* to find a diagnosis, or relevant treatments, the patient must add a *legal pilgrimage*. In the majority of cases, when a doctor assesses that the patient has one or more CSS and therefore should not continue working, the medical evaluation boards think otherwise. This leads the patient to a long, costly and stressful process through judicial courts trying to obtain a pension when the illness keeps him or her from working. This legal process, according to Katherine Lippel, Canada’s Research Chair on Occupational Health and Safety Law, may worsen the person’s health⁵⁴. The Swedish sociologist, Pia Bülow, in her research with women with CFS/ME, also states that being denied economic help undermines the person’s strategies to live with the illness⁵⁵.

To deny pensions to people with CSS asserts a strong control over them. It keeps them from complaining or developing collective protests for fear of reprisals. They may be denied a

medical report which properly reflects their limitations or economic help when they are evaluated by the government medical evaluators. It is a lot easier to discipline ill people if they have economic problems, are waiting to receive a pension⁵⁶, or if they already have a pension and live with the fear of the annual re-evaluations⁵⁷.

A qualitative revision amongst Spanish FMS, CFS/ME and MCS associations, show that the high rate of suicides found among sufferers⁵⁸ occurs most frequently when the ill person is denied disability subsidies and is forced to go back to work despite being too sick to do so⁵⁹. This puts in evidence the extreme desperation caused by the lack of social and economic support that people with CSS suffer. Suicides, like the hunger strikes that are being carried out by people with CSS for the same reasons⁶⁰, are an invitation for society to see what they do not want to see⁶¹. And what society does not want to see is that poverty is one of the main problems for people with CSS who most often live with very small pensions, no pensions at all or with no other source of income⁶². This drives many to become “the invisible homeless”⁶³ and to live in places and circumstances which damage their health further.

5. *Verbicide*: Words to control

Language used by governments, doctors, psychologists, other health professionals, and the mass media is the first and most powerful tool used to control people with CSS and their lives⁶⁴. There are numerous examples of *verbicide* in government policies, especially planning documents⁶⁵, in which doctors are trained to work with CSS⁶⁶. And, in general, the way these illnesses are represented in social language delegitimizes those who have CSS. By falsely defining the aetiology of these pathologies as psychological or “moral”, instead of organic⁶⁷, the medical establishment relegates those ill to the land of the “lazy”, “fakers” and “neurotic” which in turn gives social permission to such disempowering and delegitimizing comments as: “but you don’t look sick” and “you could make more of an effort”.

But perhaps the most poignant example of *verbicide*, this linguistic violence, is the use of Cognitive Behavioural Therapy as a form of treatment for these new illnesses. In Europe and North America, health administrations are trying to cover up the lack of proper health services for people with FMS, CFS/ME and MCS by saying that Cognitive Behavioural Therapy (CBT) is, erroneously, a “treatment” for these pathologies^{68 69}. Research shows that, besides being a way of avoiding provision of real treatments, public administrations use CBT as a way to forward their agendas of preventing people with CSS from getting pensions. Using CBT, patients are humiliatingly told they are having “inappropriate thoughts” and that they can go back to work after 10 weeks of this therapy. This strategically permits governments to avoid the inevitable cost of financial aid to people with CSS too ill to work⁷⁰.

6. Blaming the “useless” bodies

The reality is that no matter how much supporters of CBT pressure people with CSS to “pull themselves up by their bootstraps”, the physical limitations of these illnesses is often greater than in many cases of Multiple Sclerosis⁷¹. At an early age, the ill person loses his or

her family role, social life, career and savings. Or in the case of children and adolescents with CSS, they are unable to create a career or financial independence. Not being able to be a “useful body” and produce for the system⁷², causes the ill person to feel guilt which is reinforced by social commentaries such as: “You are so lucky to be able to stay home and not work!”

The guilt is even greater for a woman with CSS as the male-dominated society reminds her, day after day, that she is not carrying out her expected role as the family manager⁷³. And not only can she not look after others as she did before, she now needs help herself. This alters family and social relations enormously.

When a person has Multiple Chemical Sensitivities, the alteration in family and social relations is even greater. The ill person needs the understanding and active cooperation of family and social networks in order to avoid being exposed to chemical products which worsen their condition. Perfumes, after-shave lotions, detergents and fabric softeners, house-cleaning products, air-freshners, pesticides and many other products can create severe physical symptoms. To the physical isolation of staying inside an Environmentally Controlled home⁷⁴, the person with MCS must also add emotional isolation from human community because they are not understood or believed⁷⁵.

This gender discrimination is also experienced by women with CSS at the doctor’s office where symptoms such as pain and extreme fatigue are seen as “women’s complaints” and not taken as seriously as when a male patient reports the same symptoms⁷⁶. Organic illnesses which produce fatigue are the most questioned and delegitimized by health professionals⁷⁷. And if on top of it, the patient is a woman, it is more likely that will be diagnosed with depression than a man exhibiting the same symptoms.

There is another type of guilt imposed on the person with CSS, whether male or female. In a society where one is made to believe that good health is the result, in part, of a “positive” and “appropriate” attitude, each fluctuation and deterioration is seen by the person’s social milieu, doctors and psychologists, as an act of irresponsibility⁷⁸.

Guilt is also the main tool that doctors, educational systems and administrations use against parents of children and adolescents with CSS. It serves their interest to ignore the scientific evidence that shows the high incidence of CFS/ME amongst these age groups. Preferring not to provide medical, economic and social support to these families, the institutions use guilt (“you should admit that you have not been good parents”) and the threat of losing the custody of their children in order to silence and control the growing number of families living with CSS children.

In Western society, a few individuals with recognized illnesses or handicaps are seen as heroic: the young man who went around the world in his wheelchair, the politician who continues his public life despite having cancer, etc.⁷⁹. But people with CSS are never seen as “disabled heroes”, even though many would experience sitting up for half an hour to follow a conversation equivalent to climbing Mt. Everest. None of the heroic acts that people with CSS must perform in their daily lives such as getting out of bed to go to the bathroom, showering without fainting or crossing the street, are seen as indicators of “a life well lived”. They are not viewed in the same way that as a successful career would be.

To culpabilize is an efficient strategy for individualizing illness. It makes the ill person

feel that he or she is alone with their problem. Power structures aim to discourage collective thinking and to make sure that no one realizes that a high percentage of the population lives with CSS, and it is an important social problem around which people might organize.

7. The mobilizing potential of Central Sensitivity Syndromes

In the 21st century, people with CSS are beginning to organize themselves, breaking their individual isolation through new technologies, and demanding their rights through important educational and political actions⁸⁰. Although their main tasks continue to be medical and legal pilgrimages, and simply surviving economically and emotionally, there is a growing consciousness about their exclusion and the injustice they live with. They are developing model citizenship and political participation⁸¹.

But the rest of civil society has not yet grasped the mobilizing potential that CSS offer. The situations created through these illnesses are an example of a crisis in hegemony, an “organic crisis”, as Gramsci called it, which is not an immediate event but a process. There is an amazing opportunity for society to become more politically and socially aware by examining the link between environmental injustices (which besides being one of the main causes of CSS are also partly responsible for the important increase in cancer rates), economic and gender inequalities, abuses by the medical establishment and the pharmaceutical companies, the anti-social and privatizing policies of governments and the lack of protection of children and youth with these new illnesses.

The ecological, feminist and labour movements, the independent Left and health professionals who want to demonstrate real empathy have the potential for a catalytic moment in their hands. Through the issues brought into clear focus by CSS, there is a golden opportunity to create alliances and to join ideas and actions that will build a more just world.

(Registered in the Barcelona Registro de Propiedad Intelectual 2010)