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### Abstract

The article analyzes a number of conditions that allowed the brain to become established as an etiological hypothesis in the case of chronic fatigue syndrome (CFS), together with other hypotheses related to organic causes, such as viruses and immunity. It also addresses the process of cerebralization of personhood, which grew out of the use of neuroimaging for research and diagnostic purposes and according to which the brain constitutes the prime place for looking for the cause of the diseases – including CFS – within the context of a somatic culture, intensified at the end of the twentieth century.

Keywords: chronic fatigue syndrome; cerebral subject; neuroimaging.

The history of chronic fatigue syndrome (CFS) began in the 1980s with the publication of several series of clinical cases that described the disease with symptoms similar to the delayed effects of viral infection, manifested by fatigue and other symptoms, in large part subjective and apparently associated with serological evidence of prolonged infections due to the Epstein-Barr virus (Wessely, 1989).

Chronic fatigue syndrome, in addition to being considered an updated version modernization of nineteenth century neurastenia<sup>1</sup>, is found in the broader scenario of the so-called emerging functional syndromes at the end of the twentieth century, such as fibromyalgia syndrome, irritable bowel syndrome, pre-menstrual syndrome, temperomandibular joint disorder and cardiac pain syndrome, as well as interstitial cystitis and multiple chemical sensitivity. As for symptoms, according to the definition of Fukuda et al. (1994), the CFS diagnosis requires the presence of persistent or recurring fatigue, with a defined beginning, and at least four to eight specific subjective complaints (substantial loss of short-term memory and concentration, sore throat, sensitivity in the cervical or axillary lymph nodes, muscular pain, pain in the joints without evidence of arthritis, headaches of a different type – in terms of pattern and severity – compared to what the patient customarily presented before being attacked, non-restorative sleep and post exercise ailment lasting more than 24 hours). The manifestation of the symptoms should be occurring for at least six months. There is still no marker for CFS, despite its list of symptoms, to which its cause can be associated, making it thus considered a disorder in the function(s), rather than in the structure of the organism.

Some disorders emerging at the end of the twentieth century have points in common, allowing them to be grouped in what Dumit (2000) denominates 'new socio-medico disorders'.<sup>2</sup> Despite being different from each other, they are found on the border between the mental and the biological; they present indeterminate causality; they generate debates and legal disputes; and the use of neuroimaging is adopted – even though controversially – in an attempt to produce objectivity for each of the syndromes. This final point is what makes place of the brain more explicit as the etiological hypothesis for CFS.

The fact that the syndrome does not have an identified cause provides the margin for the preponderance of certain etiological hypotheses, mainly motivated by patients fighting for the recognition and legitimacy of their disease, based on the search for organic factors that could explain the clinical picture – and, in the case of specialists, by one that would help them indicate efficacious therapeutics using a predictive value for the diagnosis.

Over half of the studies of CFS between 1980 and 1995 concentrated exclusively on its physical etiology and in subsequent years little emphasis was given to research on the psychological and psychiatric factors (Prins, Van der Meer, Bleijenberg, 2006). Explanations for fatigue were sought, for example, in viral infections, the immunological system, neuroendicrine responses, dysfunctions of the nervous system and neuropsychological processes, the muscular structure, sleep patterns and the genetic composition. Although many studies pointed out irregularities in the patterns investigated, few found them in a significant number of patients and confirmed them through well controlled studies.

The brain was always included among the etiological hypotheses of disorders associated with fatigue. In the case of neurasthenia, it was the brain that supplied the individual with nervous energy and, at the same time, the organ that became exhausted. During the

emergence of that nosological category in the final two decades of the nineteenth century, the excessive demand for energy in certain areas of the body (the stomach or sexual organs, for example) was believed to have the effect of draining brain energy and, as a consequence, causing its exhaustion. Analogously, an excess charge of an intellectual (read, cerebral) nature would be able to produce symptoms in other parts of the organism, such as the digestive or reproductive system.

In CFS, the explanatory hypotheses reinvent the brain as the etiological locus. While in neurasthenia it was the organ of depletion, in CFS it became one of the places where the disease ought to be sought using the visualization technologies available.

The specific contribution of neuroimaging to elucidation of the etiopathogenic mechanism of fatigue began at the end of the 1990s. Many of the symptoms related in CFS, such as difficulty in concentration, attention and memorization, suggest the involvement of the central nervous system (Afari, Buchwald, 2003). Based on this suspicion, researchers have investigated the relationship between the central nervous system and CFS using the structural and functional methods of neuroimaging. Above all, they use magnetic resonance (functional or otherwise), positron emission tomography (PET) and single photon emission computed tomography (Spect).

In the specific case of CFS, there are at least two central aspects in consonance that we wish to highlight in this analysis of the uses of cerebral visualization methods. The first consists of the conditions that make the cerebral hypothesis a plausible explanation for the disorders related to fatigue – which, in this case, apply both to neurasthenia and CFS, although in different ways. These conditions concern the peculiar status granted to the brain as the locus of the personal identity in the Western world during the nineteenth century and intensified during the course of the next. This is demonstrated by the relevance and social acceptance of the hypotheses that take it as the etiology of diseases and human behaviors. The second is the role of neuroimages as powerful sources in the process of simultaneously producing objectivity for the disease and the patient. In the case of CFS, the process of producing the disease lacks objectivity, since there is no somatic indicator to which its cause is associated, the imaging instruments being considered as an alternative for rectifying it; meanwhile, the patient is objectified as sick or not, which in cerebral language means having a healthy brain or not. This article is specifically dedicated to the first of these points, based on the example generated by the second, which is the use of neuroimages, although it is difficult to set the limits where one point begins and the other ends.

The cerebral hypothesis seems to us to redefine the brain as an etiological place, as initially occurred in neurasthenia, although dressed differently. In addition, it is found in the broader context of the development of neuroscientific studies since the final decades of the twentieth century, which extend investigations of the brain to include mental and behavioral disturbances, and other conditions in addition to the diseases considered neurological.<sup>3</sup> To this is added the convincing power of neuroimages in the production of scientific objectivity (Beaulieu, 2001, 2002; Dumit, 2004; Alac, 2004), which we are interested in exploring.

The first study using magnetic resonance imaging was conducted by Buchwald et al. (1992) and told of abnormalities in 78% of the 144 patients included in the study focused

on the Lake Tahoe epidemic in Nevada, compared with the 21% found in the control subjects. It should be pointed out that these alterations were, for the most part, more intense bright spots that seemed abnormal, even though there was no lesion. These spots are known as UBOs (unidentified bright objects) and appear in a variety of diseases and even in healthy subjects. The researchers concluded that they could be related to inflammatory processes in the central nervous system, as measured by the immunological system. After this first study, countless others were carried out<sup>4</sup>, of which we highlight those that we regard as examples of the problem we are considering. One of them is that of Costa, Tannock and Brostoff (1995), which concluded that CFS patients have a particular pattern of cerebral truncal hypoperfusion, from which an image resulted that combined three brain types: normal, depressed and one having CFS, with areas more or less activated in each of them.

Costa et al. (1995), in turn, proposed their research based on a pilot study that revealed a disseminated reduction of regional cerebral perfusion in the brain stem in 24 patients with CFS, compared with the healthy controls. Based on that, the perfusion in this locale was investigated in the CFS patients to see if it would differ from the normal control patients, patients with greater depression and patients with epilepsy. The hypoperfusion in the brain stem was confirmed in the CFS patients without psychiatric disorders. It was concluded that CFS patients have a specific pattern of brain stem hypoperfusion.

Tirelli et al. (1998) specifically investigated the cerebral metabolism of 18 patients affected by CFS, without associated psychiatric diagnoses, using PET scans. These patients were compared with six others affected by depression, as well as six healthy controls. The images examined 22 cortical and sub cortical areas. The PET scans showed hypometabolism in the right mediofrontal cortex and the brain stem of CFS patients compared with healthy controls. When the CFS patients were compared with depressive subjects, the latter group showed a severe hypometabolism of the medial and upper frontal regions bilaterally, while the metabolism of the brain stem was normal. The main finding was the brain stem hypoperfusion, considered by this group of authors as a marker of CFS.

The impact of the images produced by these studies almost leads us to believe that the cause of CFS really is there, where it can be seen in primary colors, but such an impression of reality needs to be more carefully debated. Research centered on cerebral investigation, such as those described, present as a point in common the use of cerebral images to demonstrate the altered pattern, leaving it 'unquestionably visible' and centering, as we have seen, on the investigation of abnormalities and unusual spots in the cerebral matter and in the regional perfusion of the brain.

In general, abnormalities related to cerebral perfusion, mainly in the frontal, parietal, temporal and occipital areas, have been detected, especially by Spect, in patients with fatigue, when compared with depressive or healthy subjects. Meanwhile, no pattern of specific alteration worthy of diagnostic prediction has been encountered. Studies involving magnetic resonance and Spect demonstrate these subtle abnormalities in CFS cases, but the functional significance and clinical usefulness of these findings remain uncertain and still await better clarification.

The clarity of cerebral types is not as evident as it might seem. The disease and its progress are often invisible in an individual case and can only be learned through a

comparison of several scans. The emphasis is then put on a comparison of individual variations so that, in this way, the supposed essence of the disease can emerge. The gathering of information on brain lesions leads to the construction of a new object, the three dimensional representation of a disease, and at the same time, the belief that the pathology is something that can be found objectively in a visual representation.

We are interested in highlighting the way in which cerebral images and the indications that they produce tend to function as demonstrative proof of the biological markers of the disease, as an objective criterion for its definition, or as evidence to be able to relate it to a pathology. In the case of CFS, up to now it has concerned hypoperfusion of the brain stem. The cerebral images produced are still considered uncertain, because they are based on preliminary studies, full of UBOs (unidentified bright objects) about which little can be explained and, nevertheless, are iconically used as proof of their neurobiological nature and even as a demonstration of the cause of these conditions. In addition, that final image is a synthesis of various cases and not how the disease probably appears in a typical case. Even so, the idea is upheld that the essence of the disease can be visualized in a scan, as well as the differences between diseased and healthy brains. The easy migration of these results, coming from a field still in development, to diagnosis and the construction of new categories of disease perhaps arises from the persuasive power of brain images, which is not found in other diagnostic tests. What is seen is a leap forward in the midst of the incontestably incipient results of the field and the determinist tone that its findings take on when mouthed by specialists, laymen, lawyers and patients.

The reduction of the cause of CFS to a possible finding like hypoperfusion of the brain stem or any other seems to us to be, at the least, an insufficient solution for the richness of psychosocial variables that come to pass the disease. Ware and Kleinman (1992) and Wessely, Hotopf and Sharpe (1998) have been analyzing the relationships between the development of the syndrome and alterations in the patients' feeling of professional success, their excess commitment and their 'excess-of-activities-as-a-lifestyle', adding data that comprise a psychosocial clinical picture for understanding this condition. These elements to which the authors call attention force us to question the understanding of CFS as a phenomenon limited only to somatic findings, as if they were the exclusively necessary substrate for the configuration of the picture.

We concern ourselves, next, with establishing the context that is the condition for the legitimacy of these explanations limited to the brain, and the foundations based on which the brain and its dysfunctions are considered a convincing etiological hypothesis with respect to disorders specifically linked to fatigue and mental disorders in general. We are interested, given what has been set forth up to now, in understanding the authority acquired by the cerebral hypothesis, based on an analysis of how the brain became a privileged object of study in medicine and how it has been sustained.

# Background of the brain as an etiological hypothesis

Since 1980, the neurosciences have produced two important and intimately inter-related changes, with direct influences on understanding the relationships between the physical

and the mental, such as the inclusion of social and moral behaviors in its field of research and the development of the tendency to homogenize the approach of neurological and mental diseases. Thereafter, a sub-division into a 'weak program' and a 'strong program' can be observed in the project for that field (Ehrenberg, 2004). The first seeks, among other aspects, the prediction of neurological diseases such as Parkinson's and Alzheimer's and progress in their treatment through the discovery of neuropathological aspects. The strong program, in turn, would identify, in physiological terms, knowledge of the brain through knowledge of itself merging, on the clinical plane, neurology and psychiatry. From this second point derives the fact that psychopathologies gradually became treated as neuropathologies, which generates the collective expectation of enabling action on the brain machine, increasing its capacity for performance and treating indistinctly its mental or neurological illnesses.

The shift of the so-called weak program to the strong is nicely illustrated by studies that investigated how the written press presented fMRI research between 1994 (at which time no article could be found) and 2004. The amount of research using this technology in the approach to relevant subjects in the human sciences rose astoundingly in the 1990s (Racine, Bar-Ilan, Illes, 2005, 2006; Illes, Kirschen, Gabrieli, 2003), bringing to light topics such as guilt, shame and religiousness and whose results contributed to the transformation of ideas and practices in the moral, legal, social and political fields, among others.

The strong tendency of the neurosciences chooses the pole of the problematic mind/body relationship – which is undoubtedly the last and represented by the brain in an even more restricted way – for its privileged focus. The advances in neuroimaging and cellular biology techniques have driven this view and contributed to this process, since never has so much access to brain functioning been obtained as is available today through techniques such as magnetic resonance tomography and positron emission tomography. Today, a few years after the so-called decade of the brain began, we still are in it, because the scientific community's efforts are undertaken in the direction of uncovering the secrets of the mind in the brain by applying this idea to disorders, with or without behavioral traces, indiscriminately.

It is important, however, to warn not only of the historical irony we are experiencing when going through a time of such reductionist hopes, but also of the amount of criticism surrounding these conjectures. We continuously presume somatic causations for behaviors, even though, simultaneously, we are more reflective, critical and relativistic in our approach to the classifications of diseases and the therapeutic modalities. According to Rosenberg (2006, p.417): "We have never been more aware of the arbitrary and constructed quality of psychiatric diagnoses, yet in an era characterized by the increasingly bureaucratic management of health care and an increasingly pervasive reductionism in the explanation of normal as well as pathological behavior, we have never been more dependent on them."

A point to emphasize in the development of the neurosciences concerns the fact that the acceptance it has received is not proportional to any innovation or definitive discovery in the field. Thus, the process of cerebralization of personhood is not the result of scientific progress, definitive advances in the knowledge of the structure and functioning of the brain or great discoveries on which a locus of authority has been built for the brain. (Hagner,

Borck, 2001). This does not mean that the development of this field has no relationship with the present state of visualization techniques, since it is undeniable that visual, noninterventionist access to the brain has increased the quota of knowledge concerning it and the illusion of control over its processes. It is highlighted here that the legitimacy of the brain as a social actor and pole of convergence of socially available explanations about diseases did not occur exclusively due to these advances, establishing itself in the social fabric not limited to medical knowledge. Perhaps precisely the contrary: research and the advance of neuroimaging techniques have achieved great development because they occupy a privileged position of interest in the scientific community, where responses considered plausible spring up for many of the dilemmas debated in the health field. It is because they are nurtured in a soil of somatic culture and of cerebralization of medical explanations that questions are addressed to these techniques regarding the essence of certain diseases. The methods of neuroimaging have sophisticated the discourse of the cerebralization of personhood, giving it substance and drive. In this context, it is necessary to understand how the brain has functioned as an explanation that is considered sufficient, having socially been given the power to be convincing and, consequently, as an etiological factor for sociomedical disorders. What forces, then, sustain the meaning of the strong program?

First, it is necessary to highlight the context of understanding the processes of health and disease as exclusively somatic dysfunctions that have been transforming our sense of identity. The sense of ourselves as psychological individuals, inhabited by internal space, formed by biology and by experience as a source of individuality and the location of our discontents, has been undergoing a process of somatization according to which we tend to define key aspects of subjectivity in corporal terms, with the biomedical conception of the body as the parameter. This tendency is nicely illustrated by the recent emergence of terms that recall this process of somatization of subjective experience – bioidentity (Ortega, Vidal, 2007), biosociability (Rabinow, 1996) or somatic individuality (Novas, Rose, 2000), for example. This somatic individuality is expressed by the codification of fears and hopes in terms of a biomedical body and by the attempt to reform, cure or perfect it, acting on it through the use of a psychopharmacological sources.

From the mid twentieth century on, we have increasingly appealed to explanations that have emphasized the biological characteristics of mental disorders and, more generically, human behaviors. We have gone on to talk about ourselves and act upon one another presupposing that our characteristics were preponderantly formed by biology. Our humor, desires, conduct and personalities are thought of as a particular neurochemical configuration that can be moderated or modulated by action on the cerebral chemistry. This process is described by Rose (2006, 2003), who denominates as neurochemical selves those individuals who emerge as the result of this process and who understand their sorrows and complaints as cerebral chemical imbalances, treatable with drugs that restore the lost equilibrium.

The distinction established, from the end of the nineteenth century on, between the neurological subject, whose symptom is located at some point in his nervous system – unbeknownst to him – and the verbalizing subject of psychopathology, psychiatry and psychoanalysis, whose symptom is unique to him, has given way to explanations that equate the verbalizing subject with the somatic subject, and in more specific cases, the

cerebral subject. Cerebral lesions and neurochemical deficits come to be the true actors of pathologies and personal experience becomes dull derivation, disembodied and an accessory to molecular biochemical processes.

It is in this context of an increasingly intense somatic culture that the process of cerebralization of personhood, or in other words, the construction of the idea that the brain and its functioning define the personal properties of human beings, develops. Throughout the nineteenth century, the brain replaced the soul as the defining organ of identity (Hagner, 1997). Few phenomena in the field of life sciences have exercised such a strong and continuous fascination as the brain and its functions. Its transformation into an organ of the soul brings as a consequence the fact that the research of mental functions, led based on cerebral functioning, has become one of the cornerstones of neuroscientific research. The emphasis on the brain to understand the mind has constituted the hinge between two substances – mind and body – or the point at which, supposedly, psychic and physical processes become transformed into one another.

In this respect, Changeux (1985, p.274) argues (based on his view as an enthusiast of the reduction of psychological phenomena to physical states) that "[the] identification of mental events with physical events never is presented as taking an ideological position, but simply as the more logical and, primarily, more fruitful working hypothesis". The author calls attention to what he considers the nullification of vitalistic theories by the findings of molecular biology. Thus, according to him, it is to be hoped that the same thing may happen with spiritualist theses and, why not include, according to the author's reasoning, psychological and psychoanalytic theories, since, in his opinion, "the separation between mental and neural activities is not justified... The identity between mental states and physiological or physicochemical states of the brain imposes itself with full legitimacy" (p.275; free translation). Therefore, there is in the strong program of the neurosciences an aspiration to offer to functional disorders the organic substrate that has yet to be uncovered. The position of this author encounters resistance in the most recent research related to the search for neural correlates for subjective experience (Crick, 1994; Crick, Koch, 1990), whose objectives go beyond neuroscientific research and have led to the constitution of a field denominated neurophilosophy (Churchland, 1986).

Since the eighteenth century, the brain has slowly been assuming a role of prominence in the formation of personal identity and of its exclusive substrate (Vidal, 2005). This process has been underway since the first phrenology research was developed, but it became more intensely developed, at least in the industrialized West, beginning in the second half of the twentieth century, causing the so-called cerebral subject or cerebrality to emerge (Ehrenberg, 2004; Ortega, Vidal; 2007; Ortega, 2008; Vidal, 2005, 2009) for a set of practices, discourses, ways of thinking of oneself and others regarding health and disease, one which is based on the idea that the brain is organ exclusively necessary for constructing our healthy or sick identity.

The cerebral subject does not exist as an autonomous entity who has effects on things. Manifestations (theoretical, practical and visual) are what enable postulating it as a view of the human being based on which practices themselves unfold. Two areas are considered paradigmatic for its development: the debates on the definition of brain death and the

use of brain scans in the establishment of neural correlates of experiences, behaviors and diseases. The process of cerebralization has developments within and outside of the philosophical, psychological and neuroscientific fields and is the condition for emergence of projects for understanding the neurosciences as areas of the human sciences that restate them in the light of knowledge of the brain, such as neuropsychoanalysis, neuroeducation, neurodidactics, neurotheology, and for the current application of neuroscientific research to the field of mental disorders.

Certainly the cerebral subject is not the only anthropological figure with origins in the natural sciences, since genetics, which inspired several forms of organic essencialisms, and immunology, may be defined as the science of discriminating self/non-self. To judge from its presence in the media, the narrative that most directly competes with the cerebral subject is surely the genomic subject. Nevertheless, questions related to the cerebral subject bring with them dilemmas more directly related to personal identity, which is not found in the genomic narrative.

The genome may have become the modern metaphor for the soul (Nelkin, Lindee, 1995; Mauron, 2001), but even so,

Comparing the explanations of the 'I' and behavior 'based on the genome' and those 'based on the brain', it turns out that the neural aspects of human nature are more directly relevant. Many philosophical and ethical questions traditionally produced by genetics and the genome acquire more relevance and urgency when re-examined in the context of the neurosciences (Mauron, 2003, p.204).

There are some empirical reasons for this (the genomes are replicable; brains are not) and others philosophical – since the genetic influences on personality and behavior need to be measured by the brain, cerebral determinism cannot be refuted. Therefore, notwithstanding the increasingly greater convergence of genetics and the neurosciences, the problems of the self and of individuality continue primarily related to the structure and functioning of the brain.

No one contests that the brain is a necessary organ for the development of vital functions and the exercise of human capacities. What merits criticism is that particularities of its functioning be considered sufficient for the formation of certain characteristics of human action: moral choices, mental pathologies, and sexual practices, among others. The use of this perspective consists in placing on the same plane the being considered based on his body and the being considered as a whole, an agent and thinking.

# Neuroimaging and its true effects

After discussing some of the lines that comprise the role of legitimacy that the brain has been acquiring as a response to mental disorders since the nineteenth century, we must take up again more specifically how this organ gains prominence and convincing power at present. The analysis of the role of cerebral images in the media and their persuasive power in the formation of what people think regarding their own bodies and themselves enable perceiving in the cerebral images facts and ideas about who we are and our diseases,

especially mental. Research and its imagetic results are slowly contributing to produce in what one sees the sensation that the brain seen is the person himself. Based on this merging of the identity of the one who has his brain visualized with his cerebral image, Dumit (2003, 2004) describes the formation of the belief in the existence of sick, healthy, intelligent, depressed and obsessive brain types.

If the researchers were only interested in statistical measurements, the brain represented visually would be superfluous and the mathematical and comparative data of the different brains would be enough. Its visual representation, however, improves the visibility of what was before no more than numbers and comparisons: "The fMRI technique thus makes visible and spatial what is otherwise invisible and temporal" (Alac, 2004, p.203). There is, however, co-dependency between the quantitative mode and the visual-spatial mode of representation, and the fMRI images simultaneously materialize both aspects. In this process of transforming numerical data into visual data, what is invisible or, at best, visualizable by graphs is transformed into a visual datum, capable of being grasped (Joyce, 2005; Beaulieu, 2002).

In this context, brain type images, by their unavoidable appeal of showing, in theory, what exists – in this case, the disease – are taken as indubitable facts and have contributed to the categorization of individuals based on their brains. The presentation of schizophrenic, depressed or normal brain image types produces the sensation that there is a categorical difference between three types of humans, who essentially correspond to their brain types, constructing the impression of a biological and positive difference between brains that can serve as scientific evidence. One of the consequences of the body conceptions coming from the images received being seen as uncontestable scientific evidence consists in supposing that our brain is, exclusively, the necessary element for us to be ourselves.

There are many ways these imaging technologies can be used. The researchers conduct their studies almost exclusively with limited samples and the details of the experiments are frequently left behind, leaving no more than two images with ideal patterns, such as 'depressed person' and 'normal control' (Dumit, 2003), that tie cerebral abnormality to a diagnosis. Being images of extreme differentiation, they give a visual sense of a clear distinction between the normal brain and the sick one, although there are schizophrenics and other patients with mental disorders whose brains seem like those of people considered healthy and vice versa, and there are also chronically fatigued people without any brain alterations. The image, nevertheless, labels and shows the supposed disease itself, as well as the sick person objectified. The risk of such practices is the separation of these images from the context that accompanies them, which contributes to their being used as an argument for the existence of a definitive difference between one brain type and another and, in some extreme cases, for a certain finding that is still undergoing investigation to be considered as the sufficient cause of the disease (Dumit, 2000). In addition, the patients come to see themselves as those who share with others, in addition to suffering, a brain type.<sup>5</sup>

In the case of CFS, we observe that it is precisely this risk of being biologically stereotyped that the patients wish to assume, since it is more worthwhile than the risk of being poorly diagnosed – read, receiving a diagnosis of mental disorders or not being diagnosed at all. The patients' acceptance of research having a biological orientation can be seen on Internet

sites. What are the objectives of these organizations? The support groups note that the absence of research constitutes an obstacle to the legitimacy of CFS and try to reverse this process (Wessely, Hotopf, Sharpe, 1998). As a result, there is a notable tendency to search for biological causes, which are considered useful, and a parallel rejection of research having a psychosocial orientation, considered enemies of the cause. Another objective is overcoming the doctors' lack of knowledge on the subject, circulating biologically oriented information packets to professionals and academic meetings.

The process of grouping patients on virtual sites, struggling on behalf of biological explanations for mental diseases, is emphatically seen in the specific case of CFS, but it has been more generally noted in the case of mental disorders as well (Ehrenberg, 2004). The National Alliance on Mental Illness (Nami)<sup>6</sup>, for example, advocates a new biological definition for mental disease that contributes to eliminate the stigma of the disease. More precisely, it defends a conception of mental disease as a disease of the brain, with which the National Institute of Mental Health (NIHM)<sup>7</sup> agrees.

There are practical reasons for the popular endorsement of equating mental diseases with those of the brain. In the case of the United States, for example, the insurance system favors this choice, stimulating a materialistic conception of the sickness, since a disease considered to be real, one that attacks the body, is better remunerated than psychogenic diseases or diseases with no medical explanation.

The Internet, in these cases, offers the potential for geographically dispersed sufferers to share experiences, new developments, references, sources and, above all, strategies to deal with doctors, insurance companies and other bureaucracies. In the specific case of CFS, a patient discussion group, the CFS Patients Discussion Group<sup>8</sup>, received 54 thousand messages from its users between mid-1995 and 1997 (Dumit, 2000). The invisibility of the disease – without organic findings and social legitimacy – finds in these sites a way to overcome that aspect and achieve some materiality. A sense of community is created among those afflicted. They share dilemmas and exchange information on treatments that are unconventional or not accredited by biomedicine. Through donations, they finance research seeking a determinant factor for the disease. Thus, virtual communities became active participants both in the dissemination of research findings and in directing financial support to a number of studies.

It is interesting to note that many support groups are focused on discussing the implications of the disease being labeled as an organic or mental disorder. Biological support for the disease is expressly sought by patients, since it supposes that a biological cause would resolve, at one stroke, two great obstacles that they face: stigmatization and the lack of seriousness with which they are treated socially and by some health professionals – who, in the absence of somatic causes, perceive them as dissemblers and do not offer them an adequate therapeutic approach; and the lack of legal support for obtaining benefits relative to medical assistance, such as retirement due to illness and others. The demonstration of a disorder in the brain indicates the lack of involvement of the mind, which is no longer an individual source of action and responsibility. One thus enters the field of a disorder with no subject, with no one to be implicated, except for brain, to which is attributed the power of inflicting the disease on the individual.

The lawyers of these groups also defend the thesis that the disease arises from some physical damage, because, as a result, syndromes and their patients are not censured and will have a better chance of receiving their health insurance rights, as in the case of any other etiopathological disease with a clear cut etiological agent. Virtual sites nicely illustrate the processes pointed out. One of them is The CFIDS Association of America, contributing for 20 years to construct the history of CFS. The objective of The National CFIDS Foundation is to obtain funding for research that looks for the 'effective cause' of CFS and its treatment and cure, as well as offering support, information and education for patients and health professionals involved with the disease. Financed by the Office of Research on Women's Health in the United States, the Trans-NIH Working Group for Research on Chronic Fatigue Syndrome site has the same objectives. Support ME is tied in with the ME Association, founded in 1976 and located in Glasgow, Scotland, with approximately ten thousand members. This association offers advisory service by phone to patients on how to act with respect to the disease and which benefits to claim.<sup>9</sup>

As can be observed, the struggle for social acceptance and legitimacy primarily occurs on two interconnected axes: the search for an organic etiology and social security coverage of the patients. Since the request is that the disease be insured similar to organic ones, an objective demonstration of its agents is needed. Given this panorama, the patients have become activists, and the climate surrounding the question is permeated by the atmosphere and rhetoric of a battle between adversaries. The studies of Wessely, Hotopf and Sharpe (1998) demonstrate that such groups choose their agendas primarily based on their lack of tolerance for conceptualizations and confrontational strategies that do not agree with biological hypotheses and that adopt an anti-mental health and anti-psychogenesis rhetoric.

Within the context of chronic disease, the inabilities of the individual to perform functions socially appreciated and expected (by the conjugal partner, parents, employees and friends) should be pointed out, all of which diminish the opportunities for maintaining relationships separate from the fact having a disease, limiting oneself to contacts with health professionals – which contributes to his perceiving himself as inadequate and dysfunctional and identifies himself as a sick person. By preference, this identity is shared in these groups, where norms are also communicated for the well-being of the participants, ranging from the bodily, medical and hygienic cares to be taken to the struggles for proving the biological basis of the disease, the latter being an emblematic example of the forms of biosociability whose development we are watching today (Rabinow, 1996).

# Know how to ask the appropriate questions

When we analyze the use of neuroimaging techniques, it is important to arm ourselves with questions that we can make use of, addressing questions to the techniques based on what this type of technology can answer (Kosslyn, 1999). It is important to be careful that this use does not lead to simplifying complex questions that depend on variables not contemplated in what cerebral visualization offers.

Most of the current research on these techniques attempts to reveal the functional architecture underlying a given ability, i.e., the scenario of processes and structures used to

carry out a specific type of task. The areas activated when a subject utilizes an ability supposedly reflect the use of such structures, and each area is characterized by its function in the implementation of a particular process. In most of the studies, an agglomeration of areas activated or deactivated was revealed, with no information regarding the flow between them.

The activation and its variation in the various areas are important indicators, used to reach a conclusion about the involvement of a process or structure in some task. In the ideal case, supposing that the processes and structures responsible for a determined task are implemented in a given part of the brain, it can be argued that the activation in that area while the subject is realizing the task is evidence that these processes were used while the subject did it. Since a process is identified with a specific anatomical place, the logic is valid. The problem is that a given part of the brain can implement more than one process, and, therefore, the results should be considered only as another source of convergence of the evidence, and not as a conclusive sign.<sup>10</sup> Therefore, the simple finding that an area has been activated, even with well-defined functional characteristics, is not enough to infer anything beyond the fact that the properties of that area contributes to the performance. That is why the demonstration that a particular pattern of cerebral activity accompanies the performance of particular types of tasks is not, in and of itself, of great interest. "Simply finding that certain areas are active when someone performs a task is not enough" (Kosslyn, 1999, p.1293). Such data are only interpretable within the context of theories that lead to specific hypotheses.

The cares needed in the use of neuroimaging, nevertheless, do not deprive them of their utility as a tool for investigating the nature of cerebral processes. More than for construction of electrochemical patterns to which a disease can be associated, they are useful to construct converging or diverging medical hypotheses regarding the phenomena under study. The most interesting development of Kosslyn's statement is the determining that some of the questions addressed to neuroimaging technologies go beyond those which it can answer, mainly because the ideas one can approach based on verification of whether or not one area is more activated than another in a given functional task are still incipient.

In the specific case of CFS, even though patterns of cerebral change in patients may be encountered, it must be questioned if these findings can be considered enough to understanding the disease. In some extreme cases, even if we find indubitable cerebral alterations in all patients afflicted with CFS, would we be able to arrive at a simple equating of these findings with their manifestations? Would CFS be the mere expression of cerebral alterations or would these changes merely comprise a mosaic of variables, like lifestyle and acceptance of excessive patterns of efficiency in work and life, among other aspects?

As we have seen, seeking the objectivity of certain pathologies has meant seeking their somasticity through methods and instruments of visual diagnostics that can go beyond the limits of the human senses. The search for an organic finding has also become a struggle of the patients, who wish to be treated, receive social benefits and mainly be accepted as sick people and not dissemblers. We have seen the prominent role of the use of neuroimages for this purpose. Even though the visual finding is inconclusive, it potentially becomes chosen as the essence of the disease. The visual expressivity is, then, used to

construct what is intended to be shown, and not just to show what is already naturally there. As a result, we believe that the use of neuroimages not only leads to the objectivation of individuals – and in the case of the disorders in question, of an individual, sick or otherwise – but also to an objectivation of the disease itself, since, given the authority attributed to the medical technologies, a physiological pattern found becomes the potential certification of the clinical condition's objectivity, which is precisely what it lacks.

### **NOTES**

- <sup>1</sup> The category 'neurasthenia' arose beginning in 1869, initially on United States soil, in the writings of neurologist George Beard. A deficient functioning of the nervous systems is attributed to neurasthenics, supposedly due to submicroscopic alterations relative to brain cell nutrition and, therefore, invisible, but real. The neurasthenic condition was characterized by a weakening of nervous energy, with differentiated degrees of severity. The symptoms were presented in a very varied manner, including gastric, ocular, gynecological and neurological. At the core of the clinical picture was nervous exhaustion, characterized by general unexplained fatigue. Neurasthenics presented easy fatigueability, which was not alleviated by sleep or rest. Paradoxically, the sufferers enjoyed good health, were well nourished and showed well-developed musculature.
- <sup>2</sup> The author highlights the attention deficiency syndrome, the chronic fatigue syndrome, the Gulf War Syndrome, multiple chemical sensitivity and, to a lesser extent, post-traumatic stress syndrome, depression and schizophrenia. The definition of these disorders include the aforementioned characteristics. It also has consequences for the medical, social, legal, scientific and economic environment, constituting a problem not only for the person so afflicted, but also for doctors, health insurance administrative agencies and researchers.
- <sup>3</sup> The bibliography on the topic of the homogenization of neurological research and studies regarding human behaviors is vast, but we specifically suggest Healy, 1999, 2002; Rose 2006, 2007; and Valenstein, 1998.
- <sup>4</sup> There is an extensive bibliography regarding utilization of neuroimaging methods in the case of CFS and new studies on the topic are being incessantly produced. To understand some of the paths and results in this field, see Buchwald et al., 1992; Schwartz et al., 1994; Costa, Tannock, Brostoff, 1995; Greco et al., 1997; Tirelli et al., 1998; Lange et al., 1999; Cook et al., 2001; and Schmaling et al., 2003.
- <sup>5</sup> The problem of cerebral types is also analyzed by Ortega (2009), in a study on the autistic neurodiversity movement. According to the author, the theoreticians of the studies of auditory deficiency demonstrated the unreal model of bodily perfection, into which the discussion regarding the deficiency is inserted. Starting from these arguments, the anti-cure rhetoric has its origin, based, above all, on the idea of autism as a way of life and not as a disease. The author calls attention to the fact that this position is preponderantly supported by the presupposition of the neurodiversity (and not psychodiversity) of those afflicted or, in other terms, by a neurological pattern that would be typical for them.
- <sup>6</sup> Nami is one of the most important American organizations dedicated to those having mental diseases. It was founded in 1979 and is represented in every American state and in more than 1100 communities throughout the country. It seeks to advocate, research, support, educate and, above all, eradicate mental disease, improving the quality of life of those who are subjected to it and their families. See http://www.nami.org.
- <sup>7</sup> NIHM is one of the main American federal government organs for research and treatment of mental disorders. It is part of the United States Department of Health and Human Services and concentrates on biomedical research on the mind, brain and behavior, seeking to improve the mental health of Americans. It is made up of 27 units and has the mission of reducing the incidence of mental disease and behavioral disorders through research that creates tools for acquiring better treatment, understanding and eventually preventing the incapacitating conditions that affect millions of Americans. See http://www.nimh.nih.gov.
- <sup>8</sup> See http://cfs-l.home.att.net.
- <sup>9</sup> See The CFIDS Association of America (http://www.cfids.org/); Trans-NIH Working Group for Research on Chronic Fatigue Syndrome (http://orwh.od.nih.gov/cfs/cfsReportsFeb00.html); Support ME (http://www.supportme.co.uk/index2.htm); and The ME Association (http://www.meassociation.org.uk/).

<sup>10</sup> In addition, another question must be considered: different strategies for completing a task produce different activation patterns. For example, if the areas activated by the mental rotation of objects is analyzed, it is necessary to consider that there are various ways of mentally moving objects in rotation: one that involves motor processes – as when we imagine somebody turning an object in a given direction – and another that does not – as when we imagine an object being turned by an external force, like the wind. A task being researched, therefore, can have diverse variations in its execution, involving the use of areas and abilities not foreseen.

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