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3.2 *Illness as embodied cultural practice. Investigating Cfs/Me in the UK*

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> «The incarnate body (in contrast to the merely biological) is the living site of a contested hegemony of power».
> R.J. Frankenberg (1992: XVIII).

Introduction

This paper is based on research undertaken in 1998 on chronic fatigue in the UK. At that time sufferers and their organizations were engaged in a fierce battle to affirm the organic nature of their affliction against the dominant psychiatric interpretation sanctioned by the medical establishment as the proper way to diagnosing and treating a condition that had increasingly come to medical and public attention during the past 15 to 20 years.

The different medical categories crafted to define such an affliction, namely Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (1), represent very different processes of constructing its nature: the former interpreting sufferers' complaints as symptoms of a psychological condition; whereas the latter referring to the same set of signs as the outcome of an organic condition of complex aetiology.

We can list CFS/ME among those controversial illnesses, whose characteristic is always a very hot debate over their nature as 'real' medical conditions (SINGER M. *et al.* 1984, COOPER L. 1997).

Neurasthenia, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome

Conditions marked by symptoms similar to those of CFS/ME are not new in our own and other societies medical history. Historical accounts of CFS/ME (DEMITRACK M. - ABBEY S. 1994, SHORTER E. 1993, WARE N. - KLEINMAN A. 1992, WESSELY S. 1991, 1994b) usually start with its parallelism with neurasthenia. Neurasthenia came to be established as a medical category at the end of 1800 by the American neurologist George Beard (1869, 1880, 1881). He revived the term to describe a set of symptoms marked by lassitude, fatigability and mental impairment, a condition supposed to affect mainly the female population of the social upper class. Beard described the condition as a neurological disease of uncertain origin, occurring along with other morbid episodes involving emotional distress (2).

However, at the turn of the century, a new line of reasoning emerged in the medical field: neurasthenia was not meant anymore to be a neurological disorder of unknown aetiology, but rather a psychological one (3). In accounting for the relationships between neurasthenia and CFS, Norma Ware and Arthur Kleinman (WARE N. - KLEINMAN A. 1992: 205) claim that both conditions have witnessed «a shift in thinking from the observation of depression-as-symptom to the positing of depression-as-cause». In this regard the conceptual histories of the two illnesses are similar.

The case of neurasthenia condenses many of the arguments that have been animating the debate on CFS/ME today, and it summarises the sort of polarisation we face today between organicist and psychiatric interpretations. During the research I have come across different views of the relationship between neurasthenia and CFS/ME: on the one hand their parallelism was taken, especially in the medical literature, as evidence of the psychological origin of the condition; on the other hand, patients' groups and associations referred to Beard's understanding of neurasthenia as a precursor of ME, to state that the latter is a complex organic condition that has been around for some time: these historical reviews can be conceived of as different strategies to sustain the legitimacy of the proposed interpretation.

We now need to look at the processes that brought the categories of ME and CFS to existance. All the historical reconstruction of the definitions of CFS and ME look at a series of famous epidemics that have been spreading in several parts of the world during the first half of the XX century, the most famous ones being those of: Los Angeles Country General Hospital (USA), Akureyri (Iceland), Adelaide (Australia), New York State (USA), Middlesex Hospital of London (UK), Rockville (Maryland, USA), Addington Hospital (Durban, South Africa), Florida Community of Punta Gorda (USA), Royal Free Hospital of London (UK), Lake Tahoe in Nevada (USA) (4).

The category of Benign Myalgic Encephalitis emerged in an editorial of the Lancet in 1956 under the title of "A New Clinical Entity" (*Editorial* 1956: 789) precisely to explain these epidemic outbreaks of uncertain aetiology. The label was meant to be no more than a symptomatic description of the condition which occurred during the epidemic at the Royal Free Hospital in 1955: 'Benign', referring to the fact that nobody died; 'Myalgic', to describe the diffuse muscle pains suffered by the patients; and 'Encephalitis', to refer to symptoms believed to be the outcome of a brain infection (ARONOWITZ R. 1992: 160). However, such an infective interpretation was challenged few years later by McEvedy and colleagues (MCEVEDY C. - BEARD A.W. 1970a, 1970b), who re-analysed the case notes of the Royal Free Hospital (MEDICAL STAFF OF THE ROYAL FREE HOSPITAL 1957), proposing a much different interpretation: that of mass hysteria (5).

The viral hypothesis emerged again in the USA when a conference was held in 1985 under the auspices of the National Institute of Allergic and Infectious Diseases on the role of the Epstein-Barr virus as possible cause of an epidemic outbreak in Nevada (Incline village on the shore of Lake Thaoe). Moreover at that time it became clear that the condition from epidemic was becoming more and more episodic with an increasing incidence on the general population (6). After few years another conference took place in 1988 supported by the Centers for Disease Control (Atlanta, USA), as the Epstein-Barr virus could not be fully satisfactory as an explanation: this conference led to the first official definition of 'Chronic Fatigue Syndrome' (HOLMES G. *et al.* 1988) (7). The main point of the definition presented by the CDC is that a diagnosis of CFS can be made only after the systematic exclusion of any other known condition capable of producing the same symptoms (including psychiatric disorders) (8).

In reaction to the CDC criteria another conference was organised in Oxford (UK) at Green College in 1990, where another set of criteria, the so called 'Oxford Criteria', was presented. The UK definition proposed to distinguish between two broad syndromes: CFS and Post-Infective Fatigue Syndrome. Despite the fact that the new criteria still emphasise the need of excluding certain psychiatric conditions, their authors state: «other psychiatric disorders (including depressive illness, anxiety disorders, and Hyperventilation syndrome) are not necessarily reasons for exclusion» (SHARPE M. *et al.* 1991). The British definition of the affliction paved the way to the psychiatric interpretation of the condition.

The reaction of UK sufferers and their organizations (ME Association, Action for ME, and Westcare) led to the set up of a National Task Force, whose outcome was a Report produced in 1994, addressed and commissioned by the Department of Health, with the declared aims of providing information about the condition, encouraging research about it, educating public and professionals about the existence of the condition and improving services for patients (*Report From The National Task Force* 1994: 8-

10). Very significantly, the Report adopts the term 'syndromes', distinguishing between ME, CFS, and Post Viral Fatigue Syndrome (PVFS), a choice that shows patients' interests and concerns in distinguishing between suspected psychiatric conditions and what they believe to be organic ones, namely ME and PVFS.

The National Task Report was presented to the Chief Medical Officer who forwarded it to the Medical Royal Colleges to receive feedback. The feedback did come, but in the form of a counter-report presented by the Royal Colleges of Physicians, Psychiatrists and General Practitioners as a reaction to the political activity of the patients' Organisations. The Royal Colleges Report (1996) proposed to drop the term ME in favour of that of CFS on the basis that ME implies a link to encephalomyelitis that is believed by the Royal Colleges to be a pathological process absent in the condition; secondly the term ME was seen as implying a single diagnostic entity, described by the Royal Colleges not only as unproved but as unlikely to be present at all; and finally because ME dismisses the psychological dimensions regarded as central by the Royal Colleges. In assessing the Royal Colleges Report the Lancet stated: «Psychiatry has won the day for now» (*Editorial* 1996: 971).

Patients' Organisations complained that all the evidence supporting the organic nature of the condition had been progressively removed by the official definitions (9): their reaction took the form of a petition that led to a meeting in March 1998 with the Chief Medical Officer who made the promise to re-consider the issue further with the Royal Colleges. In fact, patients protested that their voices were muted by the professional interests of the psychiatric medical sector. Thisconcern appears justified as it is reflected by the services available on the UK National Health Service, all psychologically oriented (10).

Body Politics and Historical Forms of Embodiment

My aim so far has been to show how the process of defining medical knowledge can be looked at in terms of a socio-political process by which several groups engage in a struggle for the definition of the nature of the illness. To a great extent the status of categories such as CFS and ME depends on the outcome of a struggle between different groups and forms of knowledge (COOPER L. 1997) (11).

In the definition of the nature of this affliction what is at stake is a struggle over who has the right to define its reality, according to which frame of reference and which interests. Simon Wessely explains why the struggle has been so fierce: «these arguments create passions because what is at stake is the issue of legitimacy: what constitutes an acceptable disease, and what is legitimate suffering, deserving of support and sympathy?» (WESSELY S. 1994a: 34).

According to Ware (WARE N. 1993, 1994), at the core of the process of delegitimisation of the CFS/ME experience is the mind-body dichotomy, setting the scene for a polarisation between organic and psychiatric aetiology, reflected in the opposition between real and non-real illnesses. In fact, the two interpretative lines which emerged through the debate construct the condition in such a way that the psychiatric explanation has been seen by patients as a denial of the existence of the condition itself, in so far as it relies precisely on the non-existence of organic evidence. A specific rhetoric of reality has been informing the debate, a rhetoric based on the biomedical definition of the body as a measure of truth and criterion of reality (QUARANTA I. 1998).

However, if we look at medical categories not as interpretations of a given reality but as practical devices for its enactment, we may conclude that there is no single reality out there, independent from our interpretative practices (12). Such an anthropological approach necessarily entail a reframing of the questions to pose, no longer in terms of 'are ME and CFS real?', but rather in terms of 'how are they made and become real in people's existence?', and the answer is neither just rooted in the intimate personal experience of sufferers alone, nor solely in the medical construction of an objectified body, but it must be searched for in the interconnections between socio-political processes, historical horizons of meanings and practices and the lived experience. My aim here is precisely to explore this process of interconnections between subjective, political and historical processes.

As we have shown medical categories, as well as cultural categories in general, are socially produced, and represent historical discursive and practical devices to meaningfully construct the body and its dys-states of being. Being social to the core medical categories entail specific values, as Allan Young (YOUNG A. 1982: 271) claimed: «Symbols of healing are simultaneously symbols of power. Specific views of the social order are embedded in medical beliefs, where they are often encoded in aetiologies and beliefs about the sources of healing power». These reflections lead us to consider the issue of the body politics in terms of how bodies are made, how their states of being are conceived of. However, what I wish to stress here is that we should integrate such a focus on 'how bodies are made' with a careful examination of 'what bodies do' in the specific context of illness, in general, and of CFS/ME, specifically. These two analytic concerns are far from being independent, as I intend to show.

In order to state immediately the theoretical background of my argument I will look at what bodies do through the experience of illness, conceiving of the latter in terms of a bodily practice, as a specific arena of production of culture and experience: willy-nilly, illness experience produces something, e.g. a different subjectivity, a different engagement in the world, a different configuration of intersubjective relationships, a different lifeworld, in a nutshell a different process of being-in-the-world.

What I want to argue is that we should look at illness as a human product that must be investigated in terms of its manifold processes of production (how it is produced and what it does produce). However, I believe that illness can be appreciated as a cultural practice only if we look at the relationship between experience and representation in constitutive and dynamic terms: as Kleinman, Das and Lock have suggested, cultural representations of suffering shape it as a from of social experience (KLEINMAN A. - DAS V. - LOCK M. 1997: XI-XII). If this is true for experience it is also true for the body: as Michel Feher pointed out, «the history of the human body is not so much the history of its representations as of its modes of construction. For the history of its representations always refers to a real body considered to be "without history"» (FEHER M. 1989: 11). Historical images of illness and the body, then, emerge as practical and symbolic means for their construction, so much so that we may talk of them in terms of historical and social processes. It is through such historical and social images that we live ourselves as positive presence in a meaningful world (13).

Nevertheless the body is not a mere product of history and society, as it is also the lived ground of existence: bodies are constituted in and by practices (MOL A. 2002) and discourses (YOUNG A. 1995) as well as they are lived sites of discourses and practices (CSORDAS T.J. 1990, GOOD B.J. 1994). In this guise, I believe we must reject any assumption of a holistic-integral form of embodiment that is primary to any historically subjective experience of it. Instead of an integral or autonomous body, we should look at the body as a process that is historical and social as well as it is personal. We should therefore talk of historical forms of embodiment rather than embodiment as such.

What I am calling for here is the need to combine an anthropology from the body (CSORDAS T. 1994: XI) with an anthropology of the body: the former concerned with 'what the body does', whereas the latter looks at 'what is done to the body' The two approaches, in fact, have the potential to be reductionist if not combined with each other. An anthropology from the body has the potential to show the active role of the body in producing culture and experience, but it runs the risk of positioning the body as a transcendent force devoid of history, whereas if we combine such a focus with an anthropology of the body we can counteract this tendency «by revealing that the body is always-already engaged in a specific social situation by means of techniques or rule governed practices which are historically and geographically contingent » (Crossley N. 1995: 43-4). I believe that only when we combine these two analytical focuses, illness can emerge as a process that is personal as well historical, produced as well as productive.

It is with this aim that I now move on to the examination of sufferers' account of their affliction, trying to show how their experiences are historical as much as they are personal, subjective as much as objectified in forms knowledge, subversive as well as embedded in power relationship, socially produced as well as active producers.

Experience, History and Power: Illness as Embodied Cultural Practice

> «Sickness is more than just an unfortunate brush with nature. It is more than something that "just happens" to people. Sickness is something that humans do in uniquely original and creative ways. Illness is a form of body praxis, of bodily action».
> N. Scheper-Hughes (1994: 232).

Chronic illness can be seen as a form of ontological assault (Garro L. 1992: 103) in the sense that it undermines the assumptions on which our daily existence rests. If the work of culture is precisely that of grounding ourselves in a meaningful world as positive presence, chronic illness represents a crisis in such a process, a crisis that calls for a re-integration. In the case of Cfs/Me this process must be looked at in the context of the general debate I have reconstructed above: in fact, as Ware (Ware N. 1992) and Cooper (Cooper L. 1997) show, the very 'nature' of Cfs/Me as an illegitimate illness adds another burden to the suffering involved in the condition.

The narrative reconstructions of the affliction tends to biographically locate its onset in concomitance with a flu-like illness, whose problematic nature emerges from the time-scale dimension involved in the persistence of the symptoms: they don't fade away as our embodied memory would expect them to do, and doctors as well as other actors (such as relatives, friends, colleagues, etc.) are incapable of understanding what is going on.

The devastation of the symptoms is described as an overwhelming experience: general fatigability, memory losses, difficulty in concentrating, sore throat, swollen glands, muscles pain, joints pain, sleep disturbances, food allergies, digestion problems, pain in the eyes, exhaustion, dizziness, are some of the symptoms usually listed by sufferers (14). To describe how these symptoms enter their existence, informants usually talk of their impact on everyday life in relation to the most proximate activities:

> «We can say that I am in bed nearly all the time, not quite all the time, and I only go out in a cab or a car because I cannot walk as far as the bus stop, and I cannot stand at the bus stop for more than five minutes, and I have a wheelchair, because I couldn't walk from the front door to the car. And if I talk for long, for instance ten minutes at the phone, I am going to be exhausted and I will have to lay down, and if I stand up for half an hour I have to lay down. And I am too tired to have more than one person to talk to me, if I have too many people there I would be exhausted quicker. I can just about to walk to the bathroom then I would wash part of myself, and going back to bed, and then wash the second part. It sounds ridiculous. ... but there seem to be no light at the end of the tunnel» Jane (40 years old, at the time of the interview affected for 4 years) (15).
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> «Generally the accepted view of the [medical] establishment is that people with ME will respond to exercise and cognitive behaviour therapy, but as I was reading the other day, people with ME are living at their limits just by living, just by walking form one room to another, they really haven't got any reserve to do exercise programs» Kiran (48, affected for 9 years).
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> «When I got ill it was really quite hard work even to lift the spoon to my mouth. If I went to the lavatory I had to decide if I had the energy to get there, it was extraordinary, I was amazed, with what brain I had I was amazed» Sally (66, affected for 11 years).

What we are facing here is the very impossibility of taking for granted everyday life and existence, which is the most proximate manifestation of the ontological assault chronic illness represents. The world itself ceases to be 'obvious': every single action requires decision and negotiation, a negotiation which is often represented in relation to the body. The latter leaves its realm of silence to start 'being present' with its demanding voice, a voice that, if ignored, leads to punishment. The body is charged with an intentionality of its own, and such an intentionality represents the very revolution involved in bodily symptoms:

> «Normally if you haven't got ME your body works and most of the things you do are automatic: you walk or you do things, whereas if you are suffering for ME you are always aware that some part of you physically can't do things. You get always information from your body to your mind telling you

> look this isn't right, you can't do it. When you are well everything is relaxed and feels as it should be» Kiran.
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> «Q- How has the relationship with your body changed through ME?
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> A- It's very mixed, well sometimes I'm angry with it because it's not doing what I want it to do. What I've done is to become very much more in contact with it, I listen to it all the time now, and this is very hard to tell because it's such a weird disease, I think perhaps there are not that many diseases where if you don't obey your symptoms you can be given a very hard time sometimes, whereas, oh what shall I say, I was in a theatre once and I was an actor and "the show must go on", whatever happens you do the show, and all actors despite how sick they are they manage to do the show, regardless. Now with this disease you can't manage to do it regardless, it simply doesn't let you» Sally.

These narratives testify of the "inescapable embodiment" (TOOMBS S. K. 1992: 134) the illness brings about. The 'ill' body leaves the realm of absence and silence to be problematized as the explicit focus of concern. It is in this sense that Drew Leder (LEDER D. 1990) uses the expression of dys-appearance. As he claims, the body as a ground of experience is always characterised by absence in so far as it tends to recede from direct experience. When it does appear «the body appears as a thematic focus of attention, but precisely in a dys state – dys is from the Greek prefix signifying 'bad', 'hard' or 'ill', and is found in English words such as 'dysfunctional'» (LEDER D. 1990: 84). The body emerges as an alien presence «that exerts upon us a telic demand» (LEDER D. 1990: 73), that is both hermeneutical and pragmatic (LEDER D. 1990: 78), in the sense that it engenders a practical and symbolic struggle against dissolution (MURPHY R. F. 1987: 223).

The body then can be seen at the very centre of the process of dissolution of the lifeworld as an active player, imposing a practice of listening to it and to its commands never experienced before. Sufferers' accounts invite us to look at bodily distress in phenomenological terms, meaning that what is being called into question through illness is the very process of being-in-the-world. Loss of confidence in the body is very much related to the lack of control over one's own life:

> «Sometimes I'm hardly sure that I'm there at all, it's as though there are rust and cobwebs that have covered me over, and there is just this little flicker of flame that I know it's me who's trying to get through [...] Sometimes I feel I've lost the proper ability to be a wife, a mother, a friend, a worker a person» Sally.

Illness brings to light the process of being in its 'negative' fashion, and in this sense illness cannot be seen as an 'event' interrupting the processual flow of existence, but rather it must be looked at as a 'change' in the embodied process of being-in-the-world. Illness is itself a process, whose peculiarity lays in the rupture it engenders regarding the previous pre-existing relationships between body, self and society. The body leaves its silence and calls for a re-orientation of our being-in-the-world, and illness can be seen as a different existential mode of being-in-the-world (16).

Chronic illness imposes a re-negotiation with the world, ourselves, others and therefore it can be seen not only as culturally performed, but also as performing reality, a reality of a different order, that is not commonsensical anymore, forcefully reflexive, that imposes ongoing negotiations, a reality that is not ontologically given but that must be objectified every time consciously: in a nutshell, we can claim that the work of culture leans out of the inchoate to the window of awareness through the illness experience.

In this fashion we can appreciate illness as a form of cultural practice, a bodily one, that produces a re-positioning of a different self in a renewed world: the experience of illness does not just require a different 'culture', it produces a different 'culture', a different process of being-in-the-world. What I am concerned with here is an anthropology from the body (CSORDAS T.J. 1994: XI), an anthropology focused on the active role played by the lived body in the culture process, in general, and in illness experience, in particular. Obviously we cannot confine such an active and productive role of the body to chronic illness, as it is the very ground of constructing and constituting ourselves in our daily existence: however, to be specific to illness experience is the fact that such a process becomes explicit, as sufferers make clear in talking of their affliction. Moreover, my argument is that such a focus cannot be divorced from an anthropology of the body, i.e. an inquiry concerned with the ways in and through which bodies are culturally patterned and informed by social practices and discourses. When we combine the two concerns then illness can emerge as an embodied cultural practice.

Having earlier on discussed the medical construction of the body, I now move on to explore the images of the body articulated by and through sufferers' narratives, in order to show how we must take into account the dynamic and constitutive relationships between subjective experience and processes of objectification of the body.

The narratives produced during the research can be seen as one of the many ways sufferers come to 'objectify' their experience, bringing-into-being discourses to give meaning to their existence. In sufferers' production of cultural discourses biomedicine comes out, from all the narratives, as a general overarching horizon of meanings to refer to in order to make sense of their problems. In accounting for the onset and cause of illness all the informants referred to one form or another of organic problem (virus, immune-deficiency, neurological dysfunction etc.). Biomedicine sets the scene for the understanding of the illness. The deep pervasiveness of the biomedical discourses must be seen in its broader socio-cultural context: the very biomedical definition of the body rests upon wider assumptions about reality and knowledge, notions that are at the very core of an 'embodied anthropology' people share in their everyday interactions with each other and with the world (17).

Sufferers appropriate biomedical discourses and concepts in a creative way in order to make sense of their experiences: in analysing their accounts to emerge as central in almost all of them is the role of the immune system as an image around which a narrative construction can take place (GOOD B. J. 1994). If every illness episode comes to question the social order in some way or another, and if every interpretation about it is not just a social one, but brings into account the social, it is with the rhetoric of the immune system that such a link becomes explicit in its fullness:

> «Q- How do you think that your life at that time affected your illness?
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> A- [...] ME is an immune deficiency disease. My immune system was lowered by the amount of stress I had a couple of years before I got ill. I was struggling to keep my work going [...] and this struggle was very undermining, plus at home things weren't going that well either. All these things lowered my immune system and I had been extremely strong and active for many years and then when this virus came along I wasn't able to resist it, and it got hold of me, also because I didn't give myself time to recover. I think that it is the immune system that is deficient and a virus then can act in a different way from what a virus usually does» Zelda (69, now recovered after 10 years of suffering).
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> «Q- Do you think there is any special link between ME and contemporary society?
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> A- I think there are two things: one is that there is a lot of pollution in the atmosphere and that lowers your immune system and makes you more vulnerable, and so there are more people get ill than used to be as a result of that, also there are a lot of stressors in society, and that lower the immune system too. The other thing is the pesticides that are used on crops and food, some people get ME or something similar to ME just from the pesticides, if they live in an area where a lot of spraying is done on the country, and their symptoms are almost identical to ME. So I think in this way modern society has made it more prevalent than it used to be» Alan (43, affected for 8 years).
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> «Q- Why do you think you've got ME?
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> A- I don't really know 'cause we don't know what the cause is yet. I think that I don't think it's one thing. I don't think it's one virus. I think it's many factors and I think a lot of it is environmental. [...] And although I think the infection is the final trigger, I think that other things in our environment

> weaken the immune system [...] And the sorts of things which weaken the immune system I think are too much use of antibiotics... it dys-regulates everything. The contraceptive pill and Hormone Replacement Therapy, again they are unnatural things in the body which upset the natural balance of the immune system. Also things like emission from cars, pesticides – they're all around us now; it's in the water, it's in the food. The hormones in food. Pesticides you just can't avoid from pet products to gardening products to things we find in our food. And all these things together, all these modern things, have a downside which is to weaken the immune system.[...] vaccinations is another trigger as well. If you have an awful lot of vaccinations again it upsets the natural immunity. So yeah, I don't really know the answer» Carla (26, affected for 4 years).

> «I was always busy never stopped. I had worked hard, played hard, holidayed hard. You know I didn't have a weekend at home, or put my feet up, or lie on a beach It might be part of the problem, that I got ill and I had nothing left to fight. All my immune system was tired» Veronica (34, affected for 9 years).

When asked about their life before the onset of the illness, about the reasons why they have became ill, about the relationships between ME and society, etc. the informants refer to the immune system as a general meaningful landscape to organise and express their views. They usually describe themselves as very busy people, driven by multiple commitments, overactive, and always rushing to keep up with a stressful life.

It is relevant here to stress the historical-bound character of the representations sufferers elaborate in their accounts, by focusing on the symbolic dimensions of the immune system, seen as a metaphorical device to place personal experience of illness and its onset in a wider moral and social context. Emily Martin shows how the imagery of the body and of its boundaries has changed in post-industrial societies: from a passive object to be guarded from outer intruders, to a permeable and open one, active and flexible in its adjusting to internal and environmental threats. In such a new image of the body the immune system is seen as playing a central role as the very measure of health. In Martin's words: «What we see emerging through the immunologists' eyes by the late twentieth century, then, is a body that actively relates to the world, that actively selects from a cornucopia of continually produced new antibodies that keep the body healthy and enable it to meet every new challenge» (MARTIN E. 1994: 37). Within such an open field (the body) the immune system plays the role of distinguishing between self and nonself, as Martin puts it: «The notion that the immune system maintains a clear boundary between self and nonself is often accompanied by a conception of the nonself world as foreign and hostile» (MARTIN E. 1994: 53). The body is seen as a constant blur open to the interaction with the external world, a world whose potential negativity is controlled by the immune system. The immune system is the one that pays for all the risks we go through, all the stressors we live by, the lifestyle we carry on. Stress at home and at work, our habits, environmental pollution, pesticides, water, food, vaccinations, antibiotics, etc. lower our immune system and the infection is just the final trigger. The biomedical discourse presented by the informants broaden its features and becomes a way to account for the entire economy of life and for its relations with the social world.

Patients' narratives point our attention to the fact that through their experience of illness a different understanding of life and society has emerged, an understanding that comes to be fully articulated through the metaphor of the immune system: the latter constitutes an imaginative field in which people readily explore their ideas about the body and society. From sufferers' accounts, in fact, society becomes an active player, potentially menacing, a context within which individuals are constantly at risk. Bodily surface disappear and the social is in the flesh. The body, in other words, becomes a landscape where personal life histories and social forces come to play their part. Society, medicine and technology emerge from the narratives as potentially dangerous, and their outcomes as un-predictable.

Related to such historical images of body and society is a specific conceptualisation of the self. Giddens talk of 'the self' in high modernity as a project «to be reflexively made» (GIDDENS A. 1991: 3), a project in which the notion of lifestyle appears as fundamental. In the age of high-modernity in fact no-one escapes (GIDDENS A. 1991: 124) the risks produced at the personal and institutional level, that is to say that the individual has to choose his/her behaviour and lifestyle to build up a narrative project of the self capable of sustaining his/her identity The risk the body is exposed to are transformed in the very risk of the self as vulnerable and incapable to resist, unless through a proper lifestyle. This is the only means the individual is left with in order to balance the difficulties of living in a risk culture (GIDDENS A. 1991: 182). Lifestyle becomes the only means to monitor a situation of institutionalised risk over which the individual has little control (GIDDENS A. 1991: 192) (18). To ground these considerations in the ethnographic material presented I wish to pay closer attention to the symptom of fatigue. Again the immune system works as the master metaphor adopted by sufferers: the lowering of its defences is experienced as a lack of energy because of which the body is not able to recover from an infection that in normal situations would not represent a threat:

> «That's why people don't get better, because they haven't got the energy to ... and when they get a little energy they use it all up, that means not to use all your energy if you want to get better and heal» Zelda.

Specific notions of time and society are central in such an economy of energy informants refer to:

> «I think that one of the problem with modern life, if you think back to the 19th century when medical technology was zero how did people get better, they convalesced. The concept of taking 6 months off was perfectly acceptable, because there was nothing else they could do, they let the body heal itself, and we've lost this concept of convalescence, it is unacceptable to be ill in the modern life, people are under a lot of pressure, jobs need to be done, we have so many options around to enjoy ourselves, fulfilment is important, we feel we are entitled to have an interesting life, we travel, we go to the cinema, we want to go out to eat, you know, we've got all these options that somebody in the 19th century didn't have, and therefore the idea of taking time off is unacceptable, so we lost this concept of convalescence, and part of the reason for that I think is because in so many areas medicine now has technology: you give someone a pill and they get better after a week two weeks four weeks you know, and therefore it's instant solutions isn't it, nothing takes very long, and then medicine comes up against something where it can do nothing, but they've lost the concept of convalescence because for most things you don't need it anymore, you just take a pill and you go home for a few days and you get better, instant solution.
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> Q- How do you think your relationship with your body has changed.
>
> A- Well I think you learn to listen to your body much more, because I think part of the unacceptability of being ill in modern life is that people push themselves because they think they can't let people down, and if they've got aches and pain they just keep going, and you don't listen to your body. With ME you begin to learn when your body says it had enough, instead of ignoring it and keep going» Tom (55, now recovered after many years of suffering).

Again, the experience of illness can be seen as an embodied process of culture production: a different view of society, self and the body emerges from the experience of illness. Society becomes an agent in the production of illness, the body as the very source of healing, and the self as a vulnerable agent that in order to survive must be put in touch with the body. What is at stake in such a process is a form of embodied knowledge, in the sense that the body is at the very core of this process of meaning production. In this regard Tom's account articulates a clear critique of the role of medicine and society in relation to illness. Illness is seen as unacceptable in relation to the modern pace of living, and medicine is conceptualised as driven by the very same assumption at the core of modern living, and as such is demystified and put back in a critical understanding. Here we can appreciate the symbolism of fatigue as expressing a form of distress in relation to the implicit dominant values at the core of 'modern life' with their stress on fulfilment through personal satisfaction at work and in social life. The symbolism of fatigue refers to the felt need for a different configuration between individual and society. As Ware writes: «Chronic fatigue syndrome served as the catalyst for a radical lifestyle transformation in which 'perpetual motion' was replaced by relaxation and rest [...] The result was the re-assertion of control, the choice of a more manageable and healthier way of living which deliberately placed personal well-being at the centre of conversion» (WARE N. 1993: 67). As already stated, willy-nilly, illness experience produces a different configuration of the relationships between body, self and society, and as such it is a productive process.

Moreover Tom's narrative points our attention to a view of the body as an active player in the process of gaining recover. Such a process of recover must be based on the very ability to rest, i.e. a way of resisting the pressure of the modern way of living that tends to interfere with the very possibility of regaining health: in contemporary society the body is not given the time it needs to heal itself. The strategies of pacing and resting comes out as necessary to allow such a process of self-healing, implying the need to adopt alternative and reflexive lifestyles:

> «What most people do, is that they constantly overdo it, and then they relapse and they rest, and that's the boom or bust problem: I feel well, I go crazy, I overdo it, collapse and I go to bed, I feel better, I overdo it, I collapse... so it's like this, up and down. And the sensible way to stop that happening is to be pacing, which is about learning your limitations, remaining within them, gradually increasing your activity but listening to your body» Carla.

The body does not just loose its boundaries, but it even becomes an incarnate source of knowledge we must learn to understand in order to be aware of what we can do, and when, which is to say also who we can, and have to be. The symptom of fatigue, the causal link found in relation to the pace of modern life, the change in lifestyle brought about by the condition, all suggest a form of distancing from the dominant values, showing how bodily symptoms come to be articulated in narratives as expression of social distress, as the very embodiment of such a distress.

Good or Bad Attachments

The dissolution of the lifeworld implies a search for meanings, and biomedicine works as a meaningful landscape to walk through for such an endeavour. Biomedicine emerges then as the 'automatic' source of possible answers to the problems engendered by illness. The concept of hegemony here is particularly useful: biomedicine is hegemonic not because it is the dominant medical system in society, but because its dominance is generally accepted by people as the appropriate means to deal with their problems (Frankenberg R.J. 1988). People refer to biomedical practioners, not because they are victims of mystification, but rather because not to do so would not make sense to them. Therefore the concept of biomedical hegemony helps us to re-think the relations between culture, individual and society in embodied terms (19).

The concept of medicalization must be re-considered as well: in medicalizing their illness ME sufferers are not victims of the dominant process of mystification of the social nature of their problems, but rather they look for meanings capable to sustain their being-in-the-world, meanings they have embodied and rely upon to be able to successfully objectify the experience of dissolution engendered by illness (20). In their auto-medicalization patients are making a clear political statement that is 'positive' in so far as it is related to their need to be-in-the-world in meaningful terms. Contrary to a certain definition of medicalization (Conrad P. 1992), here it is really a form of resisting a definition of reality felt by sufferers as oppressing, i.e. the psychiatric one with its stigma on personal responsibility (21) Auto-medicalization, as Mark Nichter has shown (Nichter M. 1998), can be looked at, in certain contexts, as a form of agency rather than as a form of mystification, though enmeshed within the hegemonic dichotomy between mind and body.

Here we need to look at medicalization in terms of a politics of symptoms attribution, meaning that there is a political dimension (related to the politics of truth and reality entailed by the debate about the condition) in the need of affirming sufferers' presence in the world, which is the need to affirm the reality of the experience of illness: the politics of truth and reality enter the existential process of being-in-the-world, i.e. power mingles with the waves of intimate experience. It should be clear by now how reductive it can be to oppose hegemony and resistance in terms of processes of objectification and subjective experience, rather than attending to the contextual, fragmented and contradictory, though constitutive, dynamic inter-relationships between them. I am arguing that we should overcome the opposition between illness and disease, between subjective experience and objectified bodies, and instead conceive of their performance as being in continuous relation and tension with one another as well as mingling with each other in the existential process of being a person, whether ill or healthy, within specific historical horizons of discourses and practices.

The affirmation of the reality of the affliction through the dominant biomedical rhetoric is in fact an integral part of their highly existential symbolic struggle against the dissolution engendered by this chronic illness and its socio-political context. In following Joost van Loon (VAN LOON J. 1998), I believe that any opposition between subjective embodiment and objectified bodies makes little sense, as this is a question to be asked ethnographically and not so much in (?)oppositive terms but rather as different forms in which the practical constitution of the body takes place in the life and socio-cultural world of the subjects. As he claims: «the issue of body-politics is not one between autonomous versus attached bodies, but between good or bad attachments. Whereas good attachments are identified as those which allow for a process of 'learning to be affected' – a transformation of subjectivity – bad attachments lead to isolation, irresponsiveness and an inability to counteract upon (alleviate) suffering» (VAN LOON J. 1998: 11). In the case under discussion, then, medicalization works as a good attachment for ME sufferers. In sustaining the organic nature of their affliction, they resist the process of delegitimization they claim to be caused by the psychiatric interpretation (BROOM D. - WOODWARD R. 1996, COOPER L. 1997, WARE N. 1992).

We must therefore socially locate cultural discourses and consider medicalization (in this particular instance) as the means through which sufferers come to appropriate a political rhetoric whose social value is extremely powerful in defining truth and reality. The powerful biomedical objectification of the body is appropriated by sufferers to ground their subjective need to affirm the reality of their suffering in the context of the medical and public debate surrounding the definition of the affliction.

Conclusion

As I hope to have shown, the several levels I have investigated in this study about CFS/ME are far from being independent. Acknowledging that the body as historical process is at the very core of our existence, we come to realise that bodily states of being are themselves socio-cultural practices. In these terms the very 'nature' of illness is re-framed: no longer is it simply the outcome either of an organic entity, or of a psychological and social distress, but rather a meaningful domain in its own right.

An anthropology of the historical forms of embodiment can help us to gain an understanding not only of the processual nature of experience and culture, but also of the power relations inscribed in them. To assume that the body is at the very centre of anthropological inquiry does not imply any kind of reductionism. It rather allows us not to mystify subjective experience as the mere result of social processes, and at the same time it sheds light on the socio-political dimensions of our most intimate experiences. In this sense anthropology is not to be seen as a form of advocacy for the powerless, as my experience in this research has taught me: «the natives can speak for themselves» (Frankenberg R.J. 1995). It rather takes the form of a critical discourse, whose aim is not that of de-mystifying social reality (22), but rather of grounding general questions in specific contexts while giving general relevance to specific issues, such as the ones raised by ME sufferers. In doing so anthropology is a negotiated form of knowledge that can produce alternative categories capable of showing us the relativity of our taken-for-grantedness, and therefore of orienting possible alternative ways of conceiving of reality and ourselves.

However, such a task must be accomplished by looking at the multifold processes of production involved in illness: in asking general questions such as "how illness is produced and what it produces", in the specific context of the public and personal aspects of Cfs/Me, we may give sufferers' voices a theoretical framework to rethink capital issues such as the relationships between experience and representation, between medically objectified bodies and subjective experience, between lay and scientific knowledge, and in doing so force ourselves to deeply investigate their mutual, yet fragmented and highly contextual dynamic interdependence. However, we must avoid the adoption of an a-historical view of embodiment: by looking at it as a product we must investigate its processes of social and historical production. In this fashion bodies emerge as constituted in and by practices and discourses as well as lived sites of discourses and practices.

To conclude we can argue that illness experience emerges as a bodily practice, a creative process, and as such it is a cultural yet specific existential mode of being-in-the-world that is produced as well as producing, enacted as well as enacting, traversed by power relations as well as active in negotiating the terms of its relationship within a historically constituted world. Once we recognise the constitutive relationship between representation and experience, bodily states of being (in health as well as in illness) emerge as cultural practices and as a specific domain of production of meaning and experience.

Notes

[1] In this paper I will use the acronyms of Cfs and ME. They will be used together when I discuss the condition in general terms, otherwise I will use the label preferred by the actors I am referring to.

[2] He called the condition the 'American nervousness' and hypothesised that it was typical only of the 'civilised world' Beard's argument about the cultural-boundedness of neurasthenia was based on the changing social organisation of western countries with its demands for brain work. Quite tellingly the Greek etymology of the term refers to a 'lack of nerves strength'.

[3] Regarding the historical precursors of Cfs, Shorter claims that it is not possible to assume neurasthenia as having a one-to-one coincidence with Cfs, in fact the former was used as a diagnostic tool in many different contexts and implying different meanings: as a synonym of general nervousness, as the male equivalent of hysteria, as a synonym for depression, as a diagnosis for idiopathic fatigue. Moreover he claims that many 19th century sufferers from fatigue did not receive a diagnosis of neurasthenia: «It is thus evident that great caution is indicated before assuming an even rough equivalency between neurasthenia and chronic fatigue» (Shorter E. 1993: 12).

[4] For a detailed discussion of these epidemics see Quaranta (Quaranta I. 1998, 1999).

[5] They proposed to drop the term of ME and to adopt (following the analogy with Anorexia Nervosa) that of Myalgia Nervosa (1970b: 15).Their argument was based on the absence of any organic evidence, and on the majority of the female population affected by the epidemic, that took place in strict circumstances, as they argue it is always the case in mass hysteria. Such a line of reasoning was picked up by Elaine Showalter (1997) in sustaining that Cfs can be looked at as a postmodern form of mass hysteria in which patients refer to their symptoms as organic ones to avoid the stigma of psychiatric illness.

[6] Many scholars arguing for the psychiatric interpretation of the condition tend to look at this shift from epidemic to sporadic cases as the outcome of a process of sufferers' self-diagnosis, fostered by the attention given by the media and the press to the condition (Wessely S. - Hotopf M. - Sharpe M. 1998). Simon Wessely (Wessely S. 1994a: 27) points out that the link between the first epidemics and the contemporary sporadic cases is mainly historical, in so far as the two conditions seem to share very little: epidemic ME was in fact contagious, acute, with evident neurological signs, whereas Cfs seem today to be non-contagious, sporadic, and with no neurological signs.

[7] The guidelines proposed by Holmes *et al.* (Holmes G. *et al.* 1988) pointed out the need to fulfil a set of criteria in order to assess the condition. These criteria are divided in major and minor criteria (and the latter in 'symptoms criteria' and 'physical ones'). Patients must fulfil the two major criteria («1. New onset of persistent or relapsing, debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms, that does not resolve with bedrest, and that is severe enough to reduce or impair average daily activity below 50% of the patient's premorbid activity level for a period of at least 6 months. 2. Other clinical conditions that may produce similar symptoms must be excluded by thorough evaluation, based on history, physical examination, and appropriate laboratory findings...» [Holmes G. *et al* 1988: 388]), plus 6 or more of the 11 symptoms criteria and 2 or more of the 3 physical ones, or 8 or more of the 11 symptom criteria. The symptoms criteria list: mild fever, sore throat, painful lymph nodes, muscle weakness, myalgia, generalised fatigue, headaches, neurological complaints, sleep disturbance, etc. The new "working case definition" is described by Aronowitz as a «Chinese menu approach to diagnosis» (Aronowitz R. 1992: 163).

[8] Many reactions to this definition arose both from patients' groups and medical professionals, the main problem for patients being the perception that the shift from an etiologic (Epstein-Barr) to a symptomatic (Cfs) definition could enforce the legitimacy of the psychiatric interpretation: as a patient wrote in a letter to the editor of the Journal where the definition was published: «a patient diagnosed with a disease must live with its label and with lay persons' understanding of that label...This new name, instead of affirming the infectious nature of the illness, reinforces its psychiatric nature» (Annals of Internal Medicine 1988: 166). As far as the medical sector was concerned the main problems were related to the exclusion criteria and the multiple somatic

symptoms required. In fact the combination of the two criteria came out to be contradictory in so far as, by the one hand, researchers have shown that psychiatric illnesses are present in over half of the cases diagnosed as Cfs (according to the proposed new criteria), rising the issue of how to establish a clear boundary (Matthews D. - Lane T. - Manu P. 1988, Manu P. - Lane T. - Matthews D. 1988). On the other hand, it is the very definition requiring multiple somatic symptoms that leads to an overrepresentation of somatoform psychiatric illnesses (Katon W. - Russo J. 1992). Moreover the new definition seems to be overlapping with that of other conditions such as fibromyalgia rising further issues in the problem of tracing boundaries. Finally the list of conditions to be excluded, and the laboratory tests required in order to do so, made the definition impossible to adopt in practical and economic terms (Demitrack M. - Abbey S. 1994). In response to these problems other definitions have been produced (Schluederberg A. *et al*. 1992, Fukuda K. *et al.* 1994) trying to reduce the list of physical symptoms in order to avoid the overrepresentation of psychiatric illness.

(9) Such evidences tend to frame the condition in terms of entero, retro and Herpes viruses, immune, neurological and endocrinological dysfunction, chemical sensitivity and environmental pollution, allergies, and so on (see Kellner R. 1991: 32-5 for a detailed review).

(10) These services included anti-depressant trials, Cognitive-Behaviour Therapy and Graded Exercise Therapy. According to the patients' organisations these treatment options are based on a psychiatric understanding of the condition that tend to dismiss their claims that there is the need to distinguish between different kinds of Chronic Fatigue, in which ME must be kept as a useful definition for those cases that are not affected by primary psychiatric disorders, and that present abnormal muscle and mental fatigability according to a variable pattern swinging between remissions and relapses.

(11) It is significant that after the end of my fieldwork ME was accepted as an official diagnostic category by the NHS. Such a success, as Ronald Littlewood has pointed out (Littlewood R. 2002, 2003), has been obtained thanks to the patients' activist groups, that is through a struggle fought mainly in the extra-scientific arena, showing the active role of social and political relations in shaping medical knowledge and practices (Smith B. 1981).

(12) Since the body and its diseases are not given outside such practices, we may agree with Annemarie Mol (Mol A. 2002) that bodies ontology is multiple: «Realism no longer entails a submission to medical doctors if "the real" isn't mapped onto the singular virtual objects they talk about, but is, instead, taken to coincide with the multiplicity of objects they practically perform» (Mol A. 1998: 162). Such a theoretical standpoint reveals how ontologies are not to be seen as transcendent but rather they must be viewed as brought about in practice.

(13) In adopting the concept of 'presence' I am referring to the work of Ernesto de Martino (de Martino E. 1995) and his reading of the Heiddeggerian *Dasein* in cultural and historical terms. In de Martino's work this is not something given once and for good, but it is conceptualised in its processual 'nature' in which cultural institutions work in its constitution and maintenance against the risk of not being: i.e., the very crisis of presence.

(14) During the interviews sufferers refused to consider the symptom of fatigue as appropriate to describe the kind of exhaustion they experience. They tend to look at it as the most visible symptom to others, but just as the peak of the iceberg in relation to their illness experience.

(15) All informants' names have been changed to safeguard their privacy.

(16) Murphy and colleagues use the concept of liminality to describe the lives of disabled people as stuck «dramatised in a rite of passage frozen in its liminal stage» (Murphy R.F. *et al.* 1988: 241). However liminality is probably better understood as a process of re-negotiating meanings and roles, i.e. lives, in different terms. Such a process leaves behind the taken for grantedness of everyday commonsense and requires a new positioning of people in the world.

(17) However it is misleading to talk of biomedicine as a monolithic institution and a given set of theories and practices. As Hahn and Gaines' collection (Hahn R. - Gaines A. eds. 1985), as well as Lock and Gordon's one (Lock M. - Gordon D. eds. 1988), show, medical knowledge and practice is made up of numerous sub-specialities, interest groups, and individuals who bring a variety of perspectives to their work. Moreover its knowledge cannot be seen as being the exclusive posses-

sion of the medical profession, as if the boundaries between expert and lay actors were closed and clearly marked, but it is rather spread within society and appropriated in many different ways both by lay and experts actors (ARKSEY H. 1994, MARTIN E. 1994).

(18) Our choices are the only way we can manage the potential dangers spread in society, a situation that leads Emily Martin to conceive of the self in terms of an «empowered powerlessness» (MARTIN E. 1994: 122): when the individual feels responsible for everything and powerless at the same time, in so far as the very possibility of controlling and managing the enormity of factors at stake in one's own health becomes overwhelming. The self comes to be trapped between the contradiction of «universal agency and helplessness» (p. 135).

(19) The body, in fact, is not a marginal element in the process of challenging and consolidating the social order and its 'givenness' By the one hand it is in fact through its inscription in the body that knowledge and the social order become hegemonic: in entering the lived experience, they disappear from awareness. It is through such a process of embodiment that the dominant order becomes 'natural', and the socio-political processes that sustain it come to be obscured in the immediacy of the lived experience. By the other hand bodily distress articulates a form of dys-ease with the social. Both these processes are performed in the depths of our intimate existence. The process of embodiment therefore can be seen as producing as much as it is hiding. Meanings perform their embodied rituals of producing humans, and at the same time they cover the process they perform (QUARANTA I. 2001).

(20) This does not mean that power, mystification, social control, depoliticization and medicalization are not useful concepts. Indeed they are, but they must be re-located within the process of embodiment (i.e. the process of coming-into-being of culture, society, and experience), and within specific socio-historical and ethnographic contexts.

(21) Broom and Woodward (BROOM D. - WOODWARD R. 1996), Ware (WARE N. 1992) and Cooper (COOPER L. 1997) all argue that in sustaining the organic nature of the illness sufferers resist the process of deligitimation they claim to be caused by the psychiatric interpretation.

(22) Allan Young, in criticising Taussig (TAUSSIG M. 1980), already expressed doubts about such a theoretical position: «How can Taussig or any anthropologist be sure that his own ideas are correctly demystified [...] all knowledge of society and sickness is socially determined, and [...] anthropologists cannot legitimately claim access to demystified facts» (YOUNG A. 1982: 276-277).

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