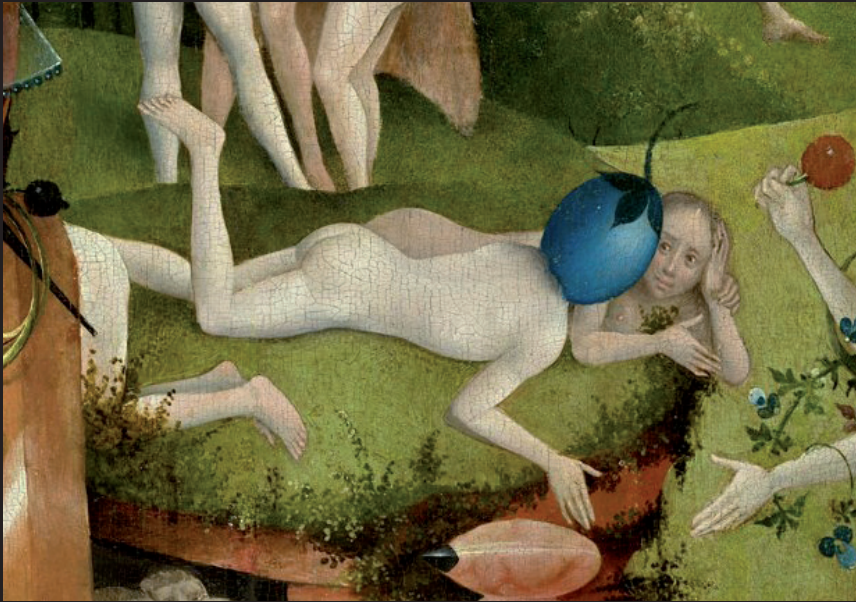


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Of Bodies and Symptoms

Anthropological Perspectives
on their Social and Medical Treatment

Edited by
Sylvie FAINZANG and Claudie HAXAIRE

OF BODIES AND SYMPTOMS

Antropologia Mèdica, 4

Colección Antropologia Mèdica

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Sylvie Fainzang & Claudie Haxaire



Tarragona, 2011

Published by:
Publicacions URV

1st edition: 2011
ISBN: 978-84-694-4991-2
DL: T-1014-2011

Publicacions de la Universitat Rovira i Virgili:
Av. Catalunya, 35 - 43002 Tarragona
Tel. 977 558 474 - Fax: 977 558 393
www.urv.cat/publicacions
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INTRODUCTION

In the field of medical anthropology, the body is a matter of constant interest, on the one hand because illness generally supposes alterations to the bodily state, which individuals attempt to control or modify, on the other hand because even when there is no illness, the desire to take action on one's body often involves recourse to a healthcare professional. Moreover, the social uses of the body and its symptoms can teach us about our societies and their evolution.

Anthropologists' interest in the body is nothing new. The reference text for this area is generally accepted as being that by MAUSS (1936) on body techniques, in other words on the ways in which human beings in different societies use their bodies. He demonstrated that the body and bodily acts are modelled *by* and *for* social authority. The socialization aspect contained within bodily practices remains topical, even though some such practices are sometimes forged *without* or *against* social authority. Indeed, it is often the position they take with regard to social authority that gives meaning to these bodily practices. In this respect his article is a foundation for more specific medical anthropology questions.

Indeed, the way in which the body invests (and is invested by) illness and medicine, raises the issue of socialisation in this field. The diverse discourses and practices of which it is the object, not only between human societies but also within each individual society, give anthropology food for comparison and provide an important object for analysis.

This is the case for new phenomena which are now being observed and which are giving medical anthropology something to discuss and question. Contemporary societies are marked by the general public's increased familiarity with medical terminology, easier access to information via new information technologies, the spreading of diagnostic criteria or the propagation of behavioural

(sexual, food-related) norms. The question of the social treatment of the body and its transformations therefore emerges in relation to stakes of varying types (economic, therapeutic, ideological, cultural, aesthetic, commercial, technical). This is the central issue of this book; it was debated in France in 2010 during an international conference on body transformations and the social uses of symptoms (<http://www.vjf.cnrs.fr/maah-france/>). Only some of the presentations have given rise to contributions in this book. These were subjected to a peer review assessment and selection process.

The body and its symptoms are a matter of interest for both social sciences and biomedical sciences, as they are at the heart of diagnostic work, even if in this respect the body alone is not sufficient to define an illness (MOL, 2002). In anthropology however, there is the cultural, political and semiological issue of learning how a bodily manifestation becomes a symptom, from the standpoints of healthcare professionals, individuals or global society, and what social response is provided. Among the issues examined in this book, are those of the visibility (or lack thereof) of symptoms (leading to different social treatments), their interpretation and their solution; all of these questions are examined either from the point of view of those who experience them, or from the point of view of healthcare professionals, or else from both standpoints, by comparing the discourses and practices which reveal either where they differ or what they have in common.

The opinions of healthcare professionals and patients can differ, particularly with regard to what doctors consider to be symptoms with no medical explanation. Mette B. RISØR examines these differences in interpretation between doctors and patients, looking at how bodily signs become symptoms and how they are interpreted in a clinical context. Using the analytical frameworks suggested by LATOUR and APPADURAI, she describes the process of “symptomization” which can be observed in Denmark. What do doctors and patients mean when they talk about “inexplicable” symptoms, and what makes them social agents? asks Mette B. RISØR. The symptoms, which she sees as “actants”, are experienced by the patients but do not fit any medical diagnosis because they cannot

be explained by any existing physio-pathological models. When the symptoms are presented to doctors, they make a diagnosis of functional disorder, as they can find no “objective” signs, whereas the patients base the objective nature of the symptom on what they feel or on their body experience of the symptom.

However, the appearance of a symptom does not necessarily mean that people turn to healthcare professionals. It may imply self-medication. In this context, Sylvie FAINZANG examines the process of medicalizing the bodily sign that has been identified as a symptom, and the pertinence of distinguishing, in this context, between signs and symptoms, as does medical semiology. This situation, which makes patients actors of their own treatment (in a process which goes from the identification of a bodily sign, through clinical self-examination, self-diagnosis and medicalization and on to self-medication) invalidates the distinction between objective and subjective symptoms, in as much as this is not what leads to differences when choosing medication. What it does show, on the other hand, is that the pertinent distinction at work for the patient is the one between symptoms with an absolute value and symptoms with a relative value, a semiological reading which is apt to generate different drug responses.

Medical anthropology has shown that a certain number of nosological entities are related to body management or to the expression of ill-being within a specific social context. This is true of burn out, chronic fatigue, French spasmophilia, fibromyalgia, etc. Yet we observe that the boundaries established between the nosological or etiological categories are constantly changing and being redefined. Between the medical discourse and so-called “lay” discourses, these boundaries cannot be superimposed. They create a discrepancy, or even a conflict, between these discourses, as can be seen from patients’ reinterpretation of the nosological and etiological categories used by doctors. Their disagreement relates either to the contours of medical categories or to their personal body condition being included in these categories.

Roberta RAFFAETÀ thus looks at the case of people in Italy who designate themselves as being allergic, a phenomenon which is sufficiently important for her to use the term “allergy epidemic”. Yet this allergy is not often confirmed by a biomedical diagnosis.

The self-diagnosis carried out by these people is based on their knowledge of the pathology, on information found in the media or through social interaction. Roberta RAFFAETÀ shows that whilst for allergologists this is an uncontrolled use of the term which goes beyond biomedical boundaries and within which they attempt to contain it, the success of this self-diagnosis relates to the fact that it is a powerful metaphor which expresses the contemporary distress that people experience in their relationships with the environment. In keeping with the works of HERZLICH (1984), she underlines the relationship with the social realm concealed within the discourse on illness, and takes it a step further, highlighting the political aspect hidden within this self-diagnosis by showing that use of the “allergy” category allows patients to take on an identity as victims of environmental conditions.

This discrepancy also occurs when patients refuse a diagnosis or an etiology. This is what happens to the people that Vibeke STEFFEN studies, whose particularity is that they encounter spirits (they hear voices or see ghosts) or have the sensation that they are deprived of energy and that their bodies are invaded by spirits. Diagnosed by doctors as showing symptoms of psychosis, these people nevertheless prefer to consult mediums, believing them to be the only ones capable of understanding, because they have had similar experiences. Vibeke STEFFEN tries to understand why they choose to manage their own symptoms without medicalizing them. She shows that the choice of spiritualism to deal with their body experience is the result of a feeling that biomedicine has stigmatised and labelled them as mentally ill, whereas they see themselves as simply having a particular sensitivity that the healthcare system is unable to take into account.

The heterogeneousness of the discourses concerning the nature of the problem, of its symptoms and their etiology, is also underlined by Madel LUZ & Rafael S. MATTOS who examine the issue of fibromyalgia, which is what people in Brazil call “pain illnesses” or “body pain illnesses”. Following an anthropological tradition which sees pain as an experience that is simultaneously biological, psychic and social, Madel LUZ and Rafael S. MATTOS look at how Brazilian women suffering from fibromyalgia manage to cope with this illness that cannot be expressed in biomedical

terms though its symptoms are chronic pains. This type of situation raises the issue of the status of symptoms and the importance that doctors attach to them. These doctors consider fibromyalgia to be a psychological illness and patients are seen as psychiatric patients due to the invisible nature of the symptoms and to the subjective character of the malaise, whereas for the women affected by this pathology, the illness is related to their professional activities and is a bodily expression of the malaise felt in the world of work, with its increasing demands for productivity creating conditions of increasing vulnerability. Focusing on the pathogenic nature of the working conditions for certain categories of personnel affected by the loss of their professional identity and the deterioration of their work, the authors examine the body practices brought into play to cope with these pains.

Increased life expectancy and new prognostic techniques raise the additional issue of living with a chronic illness, and the way in which patients define their role and their identity. Erica EUGENI uses the example of renal failure and the need for haemodialysis to examine the living conditions resulting from chronic illness and its treatment. She looks at how dialysed patients manage their chronic illness and the ensuing dependency on biomedicine, in a context where the treatment is delegated to them by the mediation of self-monitoring, but where it supposes a high level of cooperation with medical authority that imposes its norms. How do patients manage their bodies amidst this conflict between autonomy and dependence, what adjustments do they make and, as agents of their own treatment, how do they define their role as patients? These are the questions which Erica EUGENI attempts to answer. Examining the specific constraints that treatment involves for patients, she shows, in relation to the problem of agency, how patients take these constraints on board by remodelling and redefining their identity and lifestyle.

But for many chronic patients the difficulty also lies in choosing whether or not to tell people about their bodily symptoms when they are not visible – a situation which is examined by Lina MASANA. This is not solely a question of “asymptomatic” illnesses, such as hypertension can be, or of illnesses which are hard to see

from the outside, such as mental illnesses, but also of illnesses classified as medically unexplained syndromes or problems *without* any medical diagnosis, the symptoms of which are often considered to be “imaginary” or “psychosomatic”. Regarding the latter, there is the inevitable issue of the patient’s identity, with individuals being readily labelled as having a mental disorder. This invisibility can be managed in two opposite ways: making it visible or remaining invisible. Lina MASANA shows the extent to which patients are torn between these two choices, and their hesitation to make their symptoms visible is in keeping with how hard they find it to choose between the advantages and disadvantages of such visibility. To the question of knowing what social treatment might be applied to “healthy-sick” bodies, i.e. bodies affected by an invisibility (physical, social, medical, political), Lina MASANA responds by showing that if an illness is not socially recognised, the illness experience is delegitimized.

Yet the discrepancy is just as great when families find themselves diagnosed as “at risk of developing an illness” following an illness episode of one of its members, in the absence of any understandable symptom and when genetic tests prove to be insufficient because they only relate to two of the multiple coagulation factors. This is the case for thromboembolic diseases, an example examined by Claudie HAXAIRE. Whilst screening for genetic diseases raises issues of a social, political, medical and moral nature (VAILLY, 2011), it engages the body in a technique that makes it speak – which makes it say what the absence of symptoms does not. But here the genetic status itself proves to be non-pertinent and the diagnosis is made on the basis of highly statistical clinical reasoning which is difficult for people to comprehend when the manifestations of the illness, embolism or phlebitis, present extremely variable symptoms. With the body not showing any predictive symptom of the disease, and even less of the risk, we can see just how abstract such a diagnosis remains. Individuals learn to deny any such risk or to develop their own conception of it according to the various bodily manifestations – which are visible – they believe to be linked to blood circulation. Claudie HAXAIRE thus demonstrates that the greater the uncertainty,

the more important it is to find a bodily trace of the risk and thus make it tangible.

Most of the approaches discussed in this book refuse to view medical and lay discourses in a dichotomic manner. The medical discourse on the body and its uses cannot be conceived as being free from cultural values and non-scientific foundations. Josep M. COMELLES thus examines the moral dimension of the fight against obesity. Looking at the notion of excess which underlies pharmaceutical advertising messages in Spain, he focuses on cholesterol and shows how the biomedical discourse on obesity discusses excess eating. He offers a critical reading of the public health discourse and, following the trend of other works (DOZON and FASSIN, 2001; MASSÉ, 1999), underlines not only the fact that the normalization carried out by public health draws from moral registers, but also the extent to which the discourse on public health extends the link that is made between illness, evil, sin and excess, via the stigmatization of eating habits.

In contrast with the continuities that Josep M. COMELLES observes at the intersection between science, morality, medicine and religion, William SAX stresses the deep rift between the symbolic systems (traditional and modern) which coexist in India and which underpin the construction of the body, with the codification of sexuality and the attribution of standards (of beauty, strength and health) that it includes. What is the dominant ideal of the body, wonders William SAX, who examines its transformations in northern India, looking at the links that have been established between the image of the body, sexuality and health in contrasting discourses on the risks and benefits of sexual activity. He compares the traditional ideal and the modern imagery of virility, one presenting the loss of sperm as being dangerous (sperm being considered as the root of physical and mental strength) and advocating sexual abstinence, the other advocating sexual activity and putting forward a new ideal, the purpose of which is not so much health as the pursuit of pleasure. The bodily ideal is thus disconnected from the health ideal, but even more from moral and religious life. This rift is obvious when the fear that certain men have of losing their sperm is interpreted by biomedicine as a neurotic syndrome and thus medicalized and

pathologized in as much as it does not correspond to the modern scientific vision of bodily activity. In the same way, sexuality is put in the exclusive domain of the body and is ejected from the moral, ethical and religious field in which subjects traditionally place it.

The state of the body and of its symptoms is also a matter of increasing interest to the pharmaceutical industry. Pharmaceutical laboratories seize upon these states, in order to participate in the construction of illnesses which correspond to the effects of molecules born of recent pharmacological research. Various phenomena (menopause, sexual dysfunction, social phobia, shyness, etc.) have thus been medicalized to this end. In this regard, Pierre-Marie DAVID examines the operation which involves defining cholesterol as a risk factor and applying a relevant pharmaceutical object to it. Due to the biological and cultural normalization that this "inclusion" involves, it is seen as a process which is both scientific and political. Pierre-Marie DAVID adopts a science studies stance to examine the production, the availability and the prescription of statins, comparing policies and practices in the United States, the United Kingdom and France; he shows how an asymptomatic condition and its treatment are socially constructed and politically controlled. In particular, he looks at how the body is present, even in the absence of any symptoms, cholesterol being constructed as an asymptomatic risk factor. Taking a "Foucauldian" stance, Pierre-Marie DAVID stresses that the pharmaceutical inclusion of cholesterol statistics is part of a biopolitics of risk in which treating bodies means adapting them to meet a norm: he shows that whilst the discovery of statins has helped to define the illness, statins have at the same time contributed towards the definition of the normality of bodies, through the modification of levels of risk, even when they show no sign of illness.

Next to body transformations caused by illnesses and their symptoms, we have transformations and interventions on the human body, a subject of predilection for both bioethical and anthropological reflection. Although, as a social science, medical anthropology does not aim to define ethical norms, it is a necessary counterpoint to bioethics because it engages in the empirical study of the meaning and values underlying medical

practices (in relation to procreation, genetic engineering, surgery, experimentation, end of life, etc.) and of their related moral and political stakes. This involves thinking about the evolution of anthropology's role within the modern social arena, faced with the emergence of new values, new practices and new public policies relating to healthcare. How does anthropology see these issues, and how does it assume its critical position as a social science? An examination of the practices of healthcare professionals shows that the way they deal with the body and its symptoms comes from a cultural, moral or social construction which relates to a particular historical context, both with regard to therapeutic and diagnostic practices, and to the norms and values defended by the medical profession.

In truth, in order to manage the human body, its problems, issues and deficiencies, we need to agree on what the human body is and what humanity is. This is the question that Catherine RÉMY asks; she studies the impact of xenotransplantation and allotransplantation on the definition of the boundaries of the human category, in as much as the alternative solution to the lack of available organs as represented by xenotransplantation (avoiding the ethical issues raised by the instrumentalization and commodification of the body) raises other ethical questions. The bioethical issue is here pushed to extremes, because this technique uses non-human matter to create human matter. Taking two cases which have led to controversies in France and in the USA, Catherine RÉMY pursues the breach opened by LOCK (2005) and shows how for some people the techniques that are used are a way of getting around technical and ethical obstacles to taking samples from human beings, and how for others, they call into question the boundaries of humanity.

Baptiste MOUTAUD also looks at the stakes and reasoning which underlie another medical practice; he examines the use of neurosurgical technology (deep brain stimulation) to treat neurological and psychiatric disorders such as Tourette's syndrome, Parkinson's disease and obsessive compulsive disorders, thus making a contribution towards reflection on biotechnologies. He looks at how this surgical practice is applied to an "experimental" body (to use Ilana LOWY's expression, 2000) in both research

and therapy, which he refers to as “neuroscience in action”. In examining this practice, he shows that this use makes it possible to combine the interests of all actors concerned – clinicians, researchers, psychiatrists, neurologists and surgeons.

Progress in biotechnologies – the possibility of pre-symptomatic genetic tests for example – requires the introduction of special care for patients who have been told they are at risk. Knowing oneself to be “at risk” due to the revelation of predisposing genetic factors is distressing not only to the patients, but also to health professionals, when one considers the difficulty of deciding whether or not to advise patients to be genetically screened for certain illnesses when they have not actually occurred. Within this context, Bernhard HADOLT examines the issue of genetic testing for serious illnesses such as Huntington’s disease or familial breast cancer, where diagnosis takes place well before any symptoms appear. Predictive medicine raises major medical, social, political and ethical issues, with the hope of controlling the illness in question. Bernhard HADOLT’s objective is to examine the social practices induced by ethical requirements relating to different logics. He aims to show that these logics can act as a basis for modalities of genetic counselling, and that they depend on a given context (primarily institutional, but also national, political, economic and conceptual). He bases himself on research carried out in Austria and shows that it is on these contexts that the choice of model depends, in other words, that these practices are “sited”.

Of course, the values, concerns and mindsets of healthcare professionals are not homogeneous; indeed, this is the starting point for Sylvie FORTIN, who looks at the question of how individual values become a norm. Adopting a critical position and making a distinction between the personal moral values of doctors and an ethical stance, she looks at the confrontation between various value systems within a cosmopolitan clinical space, and offers an anthropological reflection which aims to disentangle the link between individual values and the norms which govern clinical practices. Here once again, body management follows norms which cannot be reduced to medical thinking but which are subject to interference from individual morals. Sylvie FORTIN shows

that not only are medical knowledge and the values of doctors intertwined in the development of the normative framework which holds sway in hospitals, but also that doctors influence medical norms in accordance with their own values.

If, as several of these contributions suggest, we must agree with HAHN (1995) that, from an anthropological standpoint, “the scientific beliefs of Biomedicine, like those of patients and non-western medical traditions, form a cultural system of principles and practices”, we cannot agree that doctors practice, *de facto*, what he refers to as “anthropological medicine”, because the cultural foundations of their manner of managing illnesses are not necessarily something of which they are aware. It is not because social and cultural conditions and events underlie the healing process that “healers *unwittingly* make anthropological assumptions about themselves, their patients and their interactions in the course of medical practice” (p. 269). The practice of anthropology does not take place “unknowingly”, in the way that Monsieur Jourdain speaks prose in Molière’s famous play *The Bourgeois Gentleman*, but with a distanced, conscious and critical outlook.

The body is more than ever placed in the centre of a vast and growing phenomenon of medicalization. Social sciences has highlighted this phenomenon, using the term “medicalization” to reflect the phenomenon by virtue of which something is “made medical”, either to hide the social causes of a phenomenon, or to ensure social control of the individuals affected by it, or to transfer responsibility for its solution, or else to biologize behaviours (alcoholism, homosexuality, hyperactivity) which were henceforth labelled as illnesses (CONRAD, 2007; LOCK & NGUYEN, 2010). This process occurs in a variety of manners, but always originates in a redefinition of categories of norms and pathologies.

The process of medicalization, initially identified and conceptualized by social sciences to theorise the extension of medical jurisdiction in the lives of individuals (ZOLA, 1972) and later more precisely defined as the process by which aspects of existence that had until then been beyond the scope of medical authority were constructed as medical problems (CONRAD, 1992,

2007), is more often than not one of the medical institution. It sometimes – and increasingly – takes place through recourse to technoscientific innovations which have led to it being referred to as “biomedicalization” in order to account for the historical shift from “control” over bodies to their “transformations”, as formulated by CLARKE *et alii* (2003: 180), for whom one dimension of the process of biomedicalization is, along with the transformation of bodies, the production of new individual and collective identities. However, as we see in several of the contributions to this book, the paternity of medicalization does not always belong to healthcare professionals; it sometimes belongs to individuals, being not just “a medicalization *involving* the lay world” (FASSIN, 1998) but a medicalization *by* the lay world. Furthermore, the medicalization (or even biologization) of a phenomenon does not necessarily mean masking the socio-political conditions which allowed the illness to occur; on the contrary, it might mean that these conditions are highlighted, as can be seen with individuals’ (political) demand for the “allergic” label, a situation in which professionals not only do not participate in the medicalization of these persons, but in fact exclude them from the process.

It thus becomes impossible to establish a dichotomy between the medical world and the lay world, partly because the latter’s knowledge feeds off the knowledge of the former in order to achieve new recompositions (namely new etiological or diagnostic constructions), and partly because the practices of the former feed off cultural or moral values, and not scientific ones (FAINZANG, 2011). Consequently, as the contributions to this book show, the management of the body and its symptoms by both healthcare professionals and individuals, is affected by many other logics than just scientific or biomedical.

These questions are valid throughout the various societies and the phenomena studied here are certainly not proper to the societies in which they are examined, even though in proper ethnographical manner, they have been put into their cultural and/or national contexts. However, they follow specific modalities in so far as globalisation has not homogenized cultures (APPADURAI, 1996) and, whether they are linked to national health systems or to cultural practices, local specificities persist. Furthermore, these

phenomena are found in both public and academic debates, the lines of which are defined by these particular contexts, making it necessary each time to put the questions into the national, social or cultural context in which they take form. The different contributions to this book illustrate this diversity, with analyses that relate to a broad range of countries: Austria, Denmark, Spain, France, USA, Italy, Quebec, Brazil and India. Through the themes it tackles and the subjects it examines, this book reveals both the universal nature of the questions it asks, and the evolution of the objects and approaches of anthropology itself, as a discipline.

References

- APPADURAI, Arjun. (1996) *Modernity At Large: Cultural Dimensions of Globalization*. Minneapolis: University of Minnesota Press.
- CLARKE Adel E., MAMO Laura, FISHMAN Jennifer R., SHIM Janet K., FOSKET Jennifer R. (2003) "Biomedicalization: Technoscientific Transformations of Health, Illness and US Biomedicine", *American sociological review* 68 (2) 161-194.
- CONRAD, Peter. (1992) "Medicalization and Social Control", *Annual Review of Sociology* 18, 209-232.
- CONRAD, Peter. (2007) *The medicalization of Society. On the transformation of Human Conditions into Treatable Disorders*. Baltimore: The Johns Hopkins University Press.
- DOZON, Jean-Pierre and FASSIN, Didier (eds.). (2001) *Critique de la santé publique. Une approche anthropologique*. Paris: Éditions Balland.
- FAINZANG, Sylvie (2011) "La culture, entre représentations de la personne et politiques de santé. Mises en perspective avec quelques données occidentales", In GODELIER Maurice (ed.). *Maladie et santé selon les sociétés et les cultures*. Paris: Presses universitaires de France, 111-127.
- FASSIN, Didier (1998) "Avant-propos: les politiques de la médicalisation", In AÏACH Pierre et DELANOE Daniel (eds.). *L'ère de la médicalisation*. Paris: Anthropos/Economica, 1-13.
- HAHN, Robert A. (1995) *Sickness and Healing. An anthropological perspective*. New Haven: Yale University Press.

- HERZLICH, Claudine (1984) "Médecine moderne et quête de sens; la maladie comme signifiant social", In AUGÉ Marc & HERZLICH Claudine (eds.). *Le sens du mal. Anthropologie, histoire, sociologie de la maladie*. Paris: Editions des Archives contemporaines (Coll.: Ordres sociaux), 189-215.
- LOCK, Margaret (2005) "Inventing a new death and making it believable", In *Lying and Illness. Power and Performance*, DONGEN (van) Els & FAINZANG Sylvie (eds.). Amsterdam, Het Spinhuis, 12-35.
- LOCK, Margaret and NGUYEN, Vinh-Kim. (2010) *An Anthropology of Biomedicine*. Chichester: Wiley-Blackwell, 57-82.
- LÖWY, Ilana. (2000) "The experimental body", In COOTER, Roger and PICKSTONE, John (eds.). *Medicine in the twentieth century*. London: Harwood Academic Publishers.
- MASSÉ, Raymond. (1999) "La santé publique comme nouvelle moralité", In Pierre FORTIN (ed.). *La réforme de la santé au Québec*, Montréal: Les Éditions Fides (Coll.: Cahiers de recherche éthique, n° 22), 155-174.
- MAUSS, Marcel. (1936) "Les techniques du corps" *Journal de Psychologie* XXXII 3-4, 363-386.
- MOL, Anne-Marie. (2002) *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press Book.
- VAILLY, Joëlle. (2011) *Naissance d'une politique de la génétique. Dépistage, biomédecine, enjeux sociaux*. Paris: Presses Universitaires de France (coll. Partage du savoir).
- ZOLA, Irving K. (1972) "Medicine as an Institution of Social Control", *Sociological Review* 20, 487-504.

THE PROCESS OF SYMPTOMIZATION CLINICAL ENCOUNTERS WITH FUNCTIONAL DISORDERS

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Introduction

Functional disorders cover a broad range of distress conditions, some less severe having little influence on one's capability to work and to perform normal daily activities while others are very severe, leading to high use of health care, sick leave and low quality of life (ROSENDAL *et alii*, 2007). A common denominator for functional disorders is the absence of a clear patho-physiological etiology contradicted by a multitude of physical symptoms. These symptoms, when experienced by the patients at a stage where no diagnosis has been made, are debilitating and worrying and naturally make the patients search for explanations and possible treatment.

Trying to capture what happens in this process of health-seeking, I followed and interviewed a group of patients in a Danish context who visited their family doctor to get help and treatment for their complaints. They had recently experienced symptoms and distress and had already seen the GP 2 to 3 times, when they accepted to be part of this study. Their GP at this point considered them as functionally ill after having made different clinical observations and basic medical tests. Informants included in this study were living, respectively, in one of the larger cities in Denmark, and in a smaller provincial town. They differed greatly in age and social background, as well as in the length of time they had been suffering from diffuse and unexplained symptoms. Repeated interviewing took place over a period of 18 months

following the patient's illness trajectories.¹ In this article I draw mainly on three illustrative cases from the material.

Symptoms and illness manifestations have been subject to anthropological analysis in many different ways, going from the experience-near narratives of patients on how to understand and make sense of what they feel in their bodies to illness brought into the social realm, either as an intersubjective construction between the sufferer and his close acquaintances or in the meeting between patient and healer (a.o. KLEINMAN, 1981; WHYTE, 1997; LOCK, 1993). Symptoms are however a dimension often taken for granted or merely assumed as being part and parcel of an illness. Symptoms as such are often not scrutinized as analytically separate or distinct items of an illness. This is not to say that anthropology has not dealt with symptoms but that they have been inherent parts of illness perceptions, narratives or symbolic worlds of distress (GOOD, 1994). In this paper the idea is pursued that symptoms may be characterized as agents following Latour's actor-network-theory (1996). Also, they may have specific social value, use and social consequences as circulating commodities - parallel to the argument brought forward by Appadurai in the book *The Social Life of Things* (1986) dealing with things as commodities having particular trajectories and social potential. More specifically, concentrating on cases with medically unexplained symptoms, the analysis focuses on the process of symptomization², of how sensations or distress become symptoms – or not – through negotiation in dominant social spaces, most importantly in clinical encounters. The paper presents a reflection and a discussion on what is understood when both patients and health professionals talk about symptoms that

¹ The empirical data consist of interviews with 9 different informants who were interviewed several times over a period of 18 months. Other publications have been made from the study focusing on idioms of illness explanations and healing processes (RISØR, 2009; RISØR, 2010).

² Symptomization in this paper is a concept used to illustrate how bodily signs become symptoms and how these circulate, are exchanged and negotiated in social processes and settings. It is not equivalent to the use of the term as almost the same as somatization, which is often seen in psychosomatics and psychiatry.

are seemingly unexplainable and how the symptoms come alive as social agents. A common trait in this is the difficulty of conveying distress to medical professionals, having distress legitimized and receiving legitimate treatment and/or social welfare – a process with several twists, turns and challenges in which I wish to take an explicit interest in the ‘symptom’ as an actant having distinct social and cultural effect. A patient with recent health complaints will often be assessed and examined for potential serious illness, depending on the symptoms and their manifestation as well as on the patient’s illness history. But here the patient suffers and brings forth his complaints in a clinical meeting with a health professional who deals with the complaints and treats them as symptoms of disease and is not able to connect them with any satisfactory organic or patho-physiological explanation and hence gives no precise biomedical diagnosis. The patient on the other hand still resides with bodily sensations and is left to deal with those in other ways. So what happens to the symptoms in such a process? What kind of transformation do they undergo and how do the symptoms act?

Bringing distress into the clinic and discovering ‘signs’

Susy, a young medical student, has experienced bad stomach cramps, headache, a sore throat, fatigue and fever for some time, sensations she is used to but that do not result in a visit to the doctor. Usually she is told by her mother not to worry because things will pass. However, she now has difficulties attending classes, while at the same time she is convinced that something is wrong with her stomach. She evaluates her stomach cramps using a variety of explanatory models (RISØR, 2009), talking about both the possible physical illness and the possibility that her pain has something to do with social distress because of her recently started studies and the social and intellectual challenges they pose. At the same time she is in doubt, at an existential level, if study is the right choice for her. After seeing the GP she says: “Well, I think it was a little odd, that I was not asked to come back, that they precisely said that now I will be checked for mononucleosis... or

for diabetes and it wasn't that and then I should have a check for mononucleosis and then I am just told that the test is negative, so well, that it is not being followed up in some way. I could of course say that I want to come in then and be examined again but there is no guarantee that I will get one of the other doctors down there who could then say something else, you see, it is somehow... then you are there... well so, this is probably also the reason why I do not see the doctor more often because when you then get to know that nothing is wrong, then I think, ok there probably isn't, it is probably just symptoms of fatigue."

The bodily sensation has been interpreted and tested by the GP to construct a medical sign which however proves negative. Susy though is still feeling bad and also disappointed because her symptom manifestation does not lead to a diagnosis or a treatment. Hence it must be 'just fatigue symptoms' indicating that she has to deal with them herself. But before seeing the GP Susy has gone through a process of symptomization interpreting her bodily signs in several ways: she has waited to see if the symptoms disappeared by themselves, she has considered possible etiologies and she has involved her closest 'therapy management group' which is her mother and her fellow students (JANZEN, 1987). Reaching a point where the bodily signs have become symptoms – legitimate symbols of disease to her – she sees the GP but the process of symptomization is stopped at the consultation because the GP operates with other standards for legitimate symptoms. This is a very clear case of the difference between symptoms and medical signs.

From a medical point of view, a symptom is 'any subjective evidence of disease. Anxiety, lower back pain and fatigue are all symptoms. They are sensations only the patient can perceive. In contrast, a sign is objective evidence of disease. A bloody nose is a sign. It is evident to the patient, doctor, nurse and other observers'.³ This definition not only explains the idea of a symptom but also contrasts it to a 'sign'. Signs and symptoms are different orders of reality (MARTÍNEZ-HERNÁNDEZ, 2000). Signs here are indices or

³ <http://www.medterms.com/script/main/art.asp?articlekey=5610>.

natural, evident signs that are interpreted (by physicians) to infer a specific disease or illness condition while a symptom refers to the patient's self-report or subjective representation of sensations. Signs belong to a natural, universal and abiographical reality (ibid) and symptoms are embedded in a biographical, cultural and social context. Susy's test for mononucleosis is done and proves negative, which confirms to the GP that the suspected symptoms of mononucleosis are not equivalent to objective signs. Hence he does not follow up on Susy's perception of her symptoms and takes no further action.

However, clinical assessments are not always that clear-cut and the GP may not always distinguish clearly between semiotic concepts, i.e. a distinction between signs and symptoms is not always made clear or felt to be important. Symptoms may become signs, signs are talked about as being symptoms or the symptoms are merely assigned to pathological categories. Medical doctors may listen to an illness presentation made by the patient, they take note of their symptoms, they may do a blood test, an x-ray, take the temperature or something else but in the end they sum up by assessing all the 'symptoms' as 'symptoms' and try to see if they make sense and indicate a certain disease/diagnosis. This is what most doctors say they do as a routine without reflecting upon whether some symptoms are subjective symptoms and some are natural signs. But from a semiotic perspective it is clear that a distinction is established between the subjective symptoms and the objective signs of disease – experience-near and experience-distant categories. This distinction also consists of different regimes of knowledge: what we may know about the body and how we know this – and also who is the person knowledgeable about which kind of knowledge! The doctor detaches herself from a patient's subjective representation of ill health and relies instead on her immediate senses and /or measurements. This is the way objective signs are established by the health professional in line with her medical education and the cultural construction of how to define an objective sign. Basically we are talking about the development of the 'clinical gaze' – *beneath a gaze that is sensitive... the symptom therefore becomes a sign* (FOUCAULT, 1973). The symptom does not become a sign unless it takes shape through

an observer skilled to discern signs – using tests and measurements to help in discerning them. In this way symptoms increasingly become subordinate to signs and produce not only a difference of subjectivity and professionalism between expressions of ill health but also a hierarchical distinction. When a patient presents symptoms they may form the basis for an inference towards which kind of disease the doctor is dealing with, that is, the symptoms become signs. But if adequacy between the medically established objective signs and the subjective symptoms is not found, or if objective signs are not found at all, a symptom presentation may point in the direction of contested illness conditions, functional disorder or bodily distress.

The process of symptomization is stopped, seen from the theoretical point of view that symptoms contain meaning and are semiotic symbols. Seen from a commodity point of view, however, the symptom did not survive as a valued commodity in a situation where it could have been exchanged (APPADURAI, 1986). But still, following Appadurai, if we say that ‘we have to follow the things themselves, for their meanings are inscribed in their form, their uses, their trajectories. It is only through analysis of these trajectories that we can interpret the human transactions and calculations that enliven things’, Susy’s process of symptomization does not stop here. She has for example talked to her mother both before and after the consultation and her mother, being a nurse, has a powerful voice in this case. She supports her daughter after her consultation, telling her that something must be done if the symptoms carry on. In the presence of her fellow students, Susy is glad to tell them they need not worry about catching mononucleosis. Legitimizing symptoms is a process also taking place in everyday life, even if they are not legitimized within the health care system. Although the symptoms fail as exchangeable commodities in the clinic, they continue to be commodities in everyday life. This is so, I argue, because her symptom manifestations evoke and refer not only to physical signs, but also to several other issues: emotions concerning her studies and social engagement, a biographical history of similar symptom events over the years, illness representations with both social, psychological and physical etiology, and expectations of

being treated with concern and interest. This social exchange dimension and cultural biography of her symptoms is not addressed or acknowledged in the consultation but her distress is instead broken down into medically relevant parts that turn out to be non-significant. In terms of an organizational context this signifies a halt in healthcare-seeking, since the health care system, through the gate keeping role of the GP, has given no medical reason for pursuing distress. A 'regime of value' has played its part and denied value to the symptom (APPADURAI, 1986) as a legitimate objective sign.

The problems of symptom presentation

When taking an empirical interest in the social spaces and situations where illness and symptoms are being negotiated and exchanged, the importance of symptom presentation becomes vivid. The following example illustrates clearly a discrepant situation. Mary, a young girl of 21, had been involved in a car accident and she relates:

I couldn't move at all, not at all, I walked totally bent over, like people who are hunchbacked [...] at that time the doctor gave me something tranquilizing, just tranquilizing [...] and I had to take it because I did not know better at the moment, I was in shock, and I did not know it, I had pain all over and I cried and I was unhappy, so I got it and I got some other pills , I think I got 4 pills that day and then I should go home for the weekend and rest and then yes, I called again Monday, I simply couldn't bear it and I was on the verge of tears, and then I had to come again . Then he wanted to send me to hospital immediately, and then I went to the County Hospital and they said they would not admit me because there was nothing wrong with me.

The example does not tell us exactly what Mary said about her condition but it does tell us a story of a clinical meeting that turns out differently than expected, a story that seems to be broken (KIRMAYER, 2000). On the one hand, we have Mary who has been badly hurt in a car accident. She feels very bad and in need of care. She has expectations of being helped but feels dismissed by the health professionals. On the other hand, we have the health professionals who actually try to help, suggesting

possibly the best solutions they know and prescribing the help or medicine as they have been taught to. In other words, to present symptoms or signs of suffering at a clinical examination is not a context-free communicative act. It implies, for example, the social consensus of what it is possible to talk about in the specific setting, in what way it is possible to communicate about this and how the cultural positions and agendas of the parties present may influence this. Illness symptoms or stories fit – or do not fit – into a medical convention of understanding, into a specific socially and culturally accepted format of how to talk about symptoms and bodily signals. In that setting the patient and the doctor seem to be the main actors. But looking closer we also have other agents or actants at play (LATOUR, 1996). An important actant here is the symptoms. The symptoms are actants because they act and prescribe action in the same way as the doctor may prescribe a pill for example. To talk about symptoms as actants is to follow Latour's actor-network theory (ANT), that is, to follow the actants in a field, to lay open the network of actants, to see the networks as simply networks and register the actants acting (*ibid.*). Taking this premise makes it important to define what actants are capable of doing, how they open up spaces of action and structure action. This is beautifully illustrated by Berg in his analysis of the creation of a medical research protocol for a randomized controlled trial (BERG, 1998). His example vividly shows how negotiations over the protocol prescribe and structure not only the specific research trial but also medical views on the patient target group and eventual medication.

In the same way, I see symptoms as actants capable of creating a space for action, as capable, for example, of constructing a pattern for a certain disease or diagnosis or at least creating an opening towards further examinations and deliberations on behalf of the health professionals. This is what is constructed in most cases when people go to see their doctors. Some of these patients may be fortunate enough to be able to fit their symptoms into a possible pattern by describing them in a lay but also often approximate medical way. Here the symptom as actant tries to become accessible to the biomedical toolkit, which the doctor possesses, through the use of language, for example – how to

express a symptom is important. Medical doctors learn to talk about pain, for example, in specific ways with agreed-upon expressions, and most of us learn the terminology of pain expression without reflecting upon it, through learning how to be healthy citizens (PETERSEN and LUPTON, 1996). Others may try to do this but without success because the symptoms fail to present themselves in a recognizable way for the health professionals – they do not fit, they are conceived as diffuse, unfocused and too shifting in their expression. In Mary's case her symptoms do release pain killers but her main symptoms seemingly do not manage to engage the doctors as is also shown here:

It is because... I could not feel my left leg, I could not move it at all [...] I had had a prickly sensation in the leg and it hurt enormously, and then I just walked (unbearable), but it got worse and worse during the evening. I was at my mother's and then I was taken to hospital by my mother's boy friend and then they kept me until the day after. Then they said, well nothing was wrong with me, but my blood percentage and my pulse did not fit quite together, but they threw me out of the door anyway and said: you are fine. And I actually never got an explanation as to why the numbers did not fit together.

Mary's 'prickly sensations' and pain somehow do not fit into the doctors' toolkit and the objective signs apparently do not support her pain condition nor give an answer to the noted imbalance and so she does not get an explanation, a diagnosis or a treatment. The process of symptomization is at a halt, interrupted by the more powerful actants in play. If we again draw on Appadurai, we may say that her knowledge of the market and the destination of the commodity (the symptom) was not sufficient (APPADURAI, 1986).

The quotation however, and her story as a whole, indicates a second dimension and difference between the meaning of *her* symptoms and the doctors' signs, that is, the social potential of the symptoms. If the symptoms were successful in gaining access to the doctors' world they would not only result in a diagnosis or at best a treatment but would also meet the expectations of the patient, the need for acknowledgement and the struggle for legitimization and existential justification. These are social concerns of patients at any time but they become especially vivid and obvious when they are not met because the symptoms are

being denied their role as actants or commodities in a clinical field and consequently do not become socially valued. Several studies have shown that those concerns are at stake for patients with functional disorders (WHITEHEAD, 2006; ÅSBRING, 2001; RISØR, 2009; NETTLETON, 2006). To be able to return from a medical visit and to tell family, friends and network what is the matter with you is a concern which is socially extremely important and decisive and which again relies fundamentally on the power of the symptom to be accepted in a medical setting. If not, several doors are closed and access to spaces of action is denied.

Negotiating symptoms in different medical realities

In Sheryl's case a negotiation about her symptoms with her GP brings her in to hospital care. Sheryl fell off her horse and hurt her back, giving her several pain sensations in her back as well as in her legs. I meet her when she has been through an operation for a prolapsed disk but still has pain and numbness in her legs, which the GP does not see as related to her back problem. Sheryl explains how she experiences this:

When you are so young, then you cannot be ill, and that is exactly the attitude of most general practitioners, that you simply cannot be seriously ill when you are 19 years old. This is what I have experienced and what I am still experiencing, instead then you are just psychically ill. And I could barely stand upright when I finally pressured them, through my general practitioner, to get me to the hospital to be examined.

Her symptomization process was related to having had several relatives who suffered from prolapsed disk and the worry that her injury may be the same. The hospital neurosurgeon confirms this and she has an operation, but visits to the GP after that continue along the same line as in the quotation, because her amount of pain does not seem to fit with her injury. One important thing in this case is that we have two different medical authorities acting differently towards the actant symptom. One denies its role and the other agrees to an overlap between subjective pain and objective signs of prolapsed disk and hence acts on it. And the GP, we are

told, apparently tries to change the focus, taking into account both her medical, social and psychological situation, by wanting to talk about her difficult upbringing and by suggesting to her to start an education or get a job, while at the same time prescribing pain killers. Sheryl, though, does not want help for anything but her medical complaints which release the pain killers and in this sense make her symptoms valuable and active. The rest of her life is no business to the GP and not part of her symptom experience. Seen from a distance, the GP makes an effort to understand Sheryl's life world in a bio-psycho-social way or even attempts to empower her (SALMON and HALL, 2004) but seen from Sheryl's point of view, he treats her in general terms without trying to take a real interest in her and thus his attempts fail. In other words the GP is not able to capture her distress as embedded in her local social world and instead her symptoms become broken down into manageable recognizable medical items – including psychological and social items. It is puzzling how doctors and patients are actually able to sit in front of each other and to apparently talk about the same things when they meet in a clinical situation, and to see how the doctor - because he/she needs to get a grip on the problem - starts to talk about and describe the patient's problem in terms of his/her personal and professional interpretations. It seems to be taken for granted that the parties involved agree on what a symptom is and how it should be described and spoken about (see also RISØR, 2009). But as the case shows this is not always so and a difference between two perceptions of one's illness experience and symptoms becomes evident. In other words the social situations and contexts seem to provide different possibilities for exchange of the symptom as commodity – or different regimes of production of knowledge (APPADURAI, 1986). This is one part of the process of symptomization that results here in a different outcome, depending on the clinical situation. Another part is the one where Sheryl deals with her symptoms herself and tries to legitimize them in her social relations and her way of living. Throughout the period of interviewing, she considers what kind of life she wants to live and tries to comply with this, by inventing strategies for house work and ordinary life, and by regulating priorities and activities according to her abilities

(cp. WARE, 1999). In this context, her symptoms have social utility and exchange value as well as social consequences for herself and her husband.

Anthropologies of signs and symptoms

From an analytical stance, symptoms are an individual's interpretation of bodily signs, distress, emotions and sensations, expressed as experience-near manifestations of feeling ill. They may not immediately be assigned to or refer to a disease pattern or a specific diagnosis however, but may merely deal with the sensation felt and its bodily experience. In this sense, patients also note having signs (but not in the medical sense) and these signs transform into symptoms in an interpretative process between the individual, his immediate social surroundings, for example 'therapy management groups', and the socio-cultural context. This is a process of symptomization where subjective sensations are interpreted through a cultural code in different settings.

Scrutinizing the meaning of symptoms according to a hermeneutic or narrative framework is the most common approach to symptoms in anthropology. Such approaches basically see symptoms as linguistic facts that evoke whole worlds of meaning and action. As an example used by Martínéz-Hernández, the expression of distress 'Oh my God' brings together both language, emotion, existential uncertainty and religious belief in one (MARTÍNEZ-HERNÁNDEZ, 2000). Local worlds of meaning and experience become visible through expressions of distress and symptoms and the works, especially of Good and Kleinman, have emphasized the importance of this. Symptoms are complex constructs to be understood as fundamentally meaningful, symbolic and narrative in their essence, often referring to whole complexes of symbols like 'heart distress' (GOOD, 1981). But apart from being linguistic facts, locally and culturally determined, symptoms are also to be approached with an emphasis on social and political-economic conditions (MARTÍNEZ-HERNÁNDEZ, 2000). Something else conditions language; this is the system of social relations within which the symptom is produced. This applies to the clinical encounters in the

cases above. Here, attention is paid to politics and power, to social inequalities and oppression, to restricting organization in health care, etc. Those are contextual matters, necessary to consider in order to create critical theory – together with and complementary to hermeneutics that enable us not to forget the understandings found in other worlds of experience. The exact context in the process of symptomization that introduces issues of power and social status may shed light on how and under which conditions a symptom gains power in certain settings, for example, clinical settings. Has a symptom already been denied a role because of dominant medical discourse or is it able to be negotiated via shared local meanings? Other researchers have pointed to the problems of linking illness manifestations too closely with accompanying illness behavior and a cultural model of illness. This does not take into account – at a societal level – issues of access and resources, personal autonomy, ability to process information or expressions of symptoms at a psychological level, nor the shifting of time, context and experience at an individual level (KARASZ AND DEMPSEY, 2008).

Anthropologists have also recently – as here – begun to investigate more closely how sensations, bodily sensations, are transformed into symptoms, that is, how are sensations acted upon, felt, interpreted and eventually pathologized. These are not examples of health-seeking behavior but analyses of what social processes sustain and/or legitimize a transformation from sensation to symptom (HINTON, HOWES and KIRMAYER, 2008; NICTER, 2008; HINTON, HINTON, REATTIDARA *et alii*, 2008; KIRMAYER, 2008). In the context of sensorial anthropology it is necessary to make clear that bodily signs may be signs that have not yet been socially constructed as symptoms and are far from being signs in a medical sense. The process from sign to symptom has been developed into a model by Hay (2008) based on field work from Lombok, Indonesia. However, we also see that inspiration from Latour and Appadurai may contribute to the study of symptoms, making it relevant to anthropology to not only ask about the meaning of a symptom, but to ask how it constructs meaning and under what circumstances, through which trajectories. In other words how and where does it – the *commodity actant*

– transform from sign to symptom to sign, what is the social use and consequence of this and how do the intersubjectively negotiated and exchangeable positions of illness and signs take place? Often peoples' management of sensations or bodily signs has been finalized before seeing, or without the need for seeing, a health professional. But when a health professional is contacted the symptom starts its trajectory and becomes a decisive actant in a clinical setting, determining the 'dancing with doctors' and hence the outcome of a consultation.

Conclusion

Summing up, symptoms are firstly linguistic manifestations expressing distress, disorder and bodily sensations that are dependent on local worlds of meaning. They refer to a biographical reality. Secondly they depend on socio-political contexts, and thirdly they depend not least on being interpreted within this context by someone in a certain social position. But social position is not everything. Symptoms are also commodities that are exchanged and they are actants, they act and prescribe what should be done, what it is possible to do, and they connect to other actants with certain social consequences. At the same time, they play an important role as legitimization of an illness condition. In this respect, to see the symptom as an actant means relieving the patient from being the ultimate responsible actor for the success or failure of the consultation. The determining power is not inherent in the patient's mental capability to express herself, nor in the medical knowledge expressed by the doctor. The structuring power of the symptom is embedded in fundamental knowledge hierarchies and socio-political contexts. If we take the starting point that symptoms do something as actants and they are able to modulate reactions from health professionals, to release certain actions and to come forward as commodities, then they also intervene in the social world and in the way patients' and doctors' relationships are constructed and what they imply – as exemplified in the cases. The hierarchical position of symptoms versus objective signs creates a distinction between individual and scientific

knowledge and this distinction informs health professionals in their knowledge of the biological body. Furthermore, we have the patient who is both material (body) and social as well as culturally determined while experiencing symptoms. Finally, in a pivotal position, patients with contested symptoms /illnesses doubtless challenge the biomedical knowledge /paradigm at a practical level, but also, their embodied experience is a result of the (im)possible expressions of the material and the social at a particular historical moment. In other words 'the coproduction of biology and culture are implicated in embodied experience and its expressions' (LOCK, 2001) and the social life of symptoms starts from there.

References

- APPADURAI, Arjun (1986) Introduction: commodities and the politics of value. In APPADURAI, Arjun (ed.) *The Social Life of Things: Commodities in Cultural Perspective*. Cambridge: University Press.
- ÅSBING, Pia (2001) "Chronic illness – a disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia", *Journal of Advanced Nursing* 34(3) 312–19.
- BERG, Marc (1998) "Order(s) and Disorder(s): Of Protocols and Medical Practices", In BERG, Marc and MOL, Annemarie (eds.) *Differences in Medicines. Unravelling Practices, Techniques, and Bodies*. Durham & London: Duke University Press.
- FOUCAULT, Michel (1973) *The birth of the clinic: an archaeology of medical perception*. London: Tavistock.
- GOOD, Byron J. and GOOD, Mary-Jo D. (1981) "The meaning of symptoms: a cultural hermeneutic model for clinical practice" In EISENBERG, Leo and KLEINMAN, Arthur (eds.) *The relevance of social science for medicine*. London: D. Reidel Publishing Company.
- GOOD, Byron J. (1994) *Medicine, rationality, and experience. An anthropological perspective*. Cambridge: University Press
- HAY, M. Cameron (2008) "Reading Sensations: Understanding the Process of Distinguishing 'Fine' from 'Sick'", *Transcultural Psychiatry* 45:198-229.

- HINTON, Devon E., HOWES, David H. and KIRMAYER, Laurence J. (2008) "Toward a Medical Anthropology of Sensations: Definitions and Research Agenda", *Transcultural Psychiatry* 45: 142-162.
- HINTON, Devon E., HINTON, Susan D., LOEUM, Reattidara J.-R., VUTH, Pich, POLLACK, Mark H. (2008) "The 'Multiplex Model' of Somatic Symptoms: Application to Tinnitus among Traumatized Cambodian Refugees", *Transcultural Psychiatry* 45: 287-317.
- JANZEN, John M. (1987) "Therapy Management: Concept, Reality, Process", *Medical Anthropology Quarterly* 1(1) 68-84.
- KARASZ, Alison and DEMPSEY, Kara (2008) "Health seeking for ambiguous symptoms in two cultural groups: a comparative study", *Transcultural Psychiatry* 45:415-438.
- KIRMAYER, Laurence J. (2000) "Broken Narratives. Clinical Encounters and the Poetics of Illness Experience". In MATTINGLY, Cheryl and GARRO, Linda C. (eds.) *Narrative and the Cultural Construction of Healing*. University of California Press.
- KIRMAYER, Laurence J. (2008) "Culture and the Metaphoric Mediation of Pain", *Transcultural Psychiatry* 45: 318-338
- KLEINMAN, Arthur (1981) *Patients and Healers in the Context of Culture: An exploration of the borderland between anthropology, medicine and psychiatry*. Berkeley: University of California Press.
- LATOUR, Bruno. (1996) "Om Aktør Netværksteori. Nogle få afklaringer og mere end nogle få forviklinger", *Philosophia* 25(3-4) 50-64.
- LOCK, Margaret. (1993) "The Politics of Mid-Life and Menopause: Ideologies for the Second Sex in North America and Japan". In LINDENBAUM, Sheryl and LOCK, Margaret (eds.) *Knowledge, Power and Practice. The Anthropology of Medicine and Everyday Life*. Berkeley: University of California Press.
- LOCK, Margaret. (2001) "The Tempering of Medical Anthropology: Troubling Natural Categories", *Medical Anthropology Quarterly* 15 (4) 478-492.
- MARTÍNEZ-HERNÁNDEZ, Angel (2000) *What's Behind the Symptom? On Psychiatric Observation and Anthropological Understanding*. Harwood academic publishers.

- NETTLETON, Sarah (2006) "I just want permission to be ill': towards a sociology of medically unexplained symptoms", *Social Science & Medicine* 62(5)1167-78.
- NICHTER, Mark (2008) "Coming to Our Senses: Appreciating the Sensorial in Medical Anthropology", *Transcultural Psychiatry* 45: 163-197.
- PETERSEN, Alan and LUPTON, Deborah (1996) *The New Public Health. Health and Self in the Age of Risk*. London: Sage Publications.
- RISØR, Mette B. (2009) "Illness explanations among patients with medically unexplained symptoms – different idioms for different contexts", *Health* 13 (5) 505-521.
- RISØR, Mette B. (2010) "Healing and recovery as a social process among patients with medically unexplained symptoms (MUS)". In FAINZANG, Sylvie, HEM, Hans Einar and RISØR, Mette B. (eds.) *The Taste For Knowledge – Medical Anthropology Facing Medical Realities*. Århus: Aarhus University Press.
- ROSENDAL, Marianne, FINK, Per, FALKOE, Erik; HANSEN, Henriette S. and OLESEN, Frede (2007) "Improving the classification of medically unexplained symptoms in primary care", *European Journal of Psychiatry* 21(1) 25-36.
- SALMON Peter and HALL, George (2004) "Patient empowerment or the emperor's new clothes", *Journal of the Royal Society of Medicine* 97(2) 53-56.
- WARE, Norma C. (1999) "Toward a model of social course in chronic illness: The example of chronic fatigue syndrome", *Culture, Medicine & Psychiatry* 23(3) 303-31.
- WHITEHEAD, Lisa (2006) "Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study. *International Journal of Nursing Studies* 43(8)1023-31.
- WHYTE, Susan R. (1997) *Questioning Misfortune. The pragmatics of uncertainty in eastern Uganda*. Cambridge University Press.

FROM SELF-DIAGNOSIS TO SELF-MEDICATION: CONSTRUCTING AND IDENTIFYING SYMPTOMS

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Anthropology has shown for a long time that the way symptoms are perceived has an impact on therapeutic recourse (KLEINMAN, 1980; GOOD & GOOD, 1981). But the appearance of a symptom does not necessarily involve recourse to a health professional; it might involve recourse to self-medication. The question is then of knowing under what conditions subjects decide to self-medicate when they are confronted with a symptom. What defines a symptom and what role does it play? On what basis does a bodily sign become a symptom? And on what basis does a symptom become a sign of the necessity to medicalize it and lead to the choice to self-medicate rather than to resort to a professional? This is the sort of questions which I will try to answer, on the basis of research undertaken in France among thirty persons. I will try to show the impact of bodily signs on the decision to self-medicate, resulting from a process of medicalizing the perceived symptom. In this regard, I will show that the semiological controversy relating to the direction in which the conversion between sign and symptom is made is irrelevant in the context of self-medication just as it is unfruitful to make a distinction between objective and subjective signs when exploring the issue of self-medication, and I will highlight the main models around which people decide to practice self-medication when identifying symptoms.

The research was led in people's homes, where I collected case-stories ('illness narratives' and 'symptom narratives') leading to self-medication, combined with observation of practices. The study consisted first in collecting material about bodily signs which have been given the status of symptoms to be treated by

self-medication. I also investigated the pharmaceuticals people had used and those they had at home, and tried to learn which ones had been acquired for self-medication, the circumstances of their acquisition and the modes of their use.

Symptoms and therapeutic recourse

Anthropology has shown that the meaning given to symptoms is the result of a cultural construction, in particular in the psychiatric field (HAY, 2008; DELVECCHIO GOOD *et alii*, 1994; MARTINEZ-HERNAEZ, 2000). Yet if the meaning of the symptom is socially acquired and culturally built, the construction of a symptom is not the result of a collective process alone. An individual construction is superimposed on it. Therefore, even if it is fueled by the various influences exerted on the subject and by his/her personal experience, thus making it the result of a social process, this construction varies according to individuals and to their specific histories. Besides, this construction not only varies according to the social and cultural context in which the subject lives (KLEINMAN, 1980; ALONZO, 1984; SAND ANDERSEN, 2010), partly conditioning the meaning which he/she gives to a symptom, different from that which his/her colleague, neighbor or kin would give to a similar symptom on his/her own body, but it is also likely to vary for any given subject at various periods of his/her life, in the somatic register.

A certain number of sociologists (AIACH & CÈBE, 1991) have examined the symptoms for which people consider a therapeutic recourse to be useful, most of them basing their studies on symptoms as defined by bio-medicine. But few have examined the issue of the perception of symptoms within the framework of self-medication – understood here as the choice to use, on one's own initiative, pharmaceuticals (in a biomedical acceptance). In these studies, the subject's perception of a symptom is seen as the decisive element which leads him/her to resort to a doctor, with specific attention being paid to the type of therapeutic resort according to social milieus (BARTHE, 1990). Yet, the reasons and conditions under which a subject, faced with a bodily sign,

considers it to be pathological and requiring treatment are not necessarily the same as the reasons and conditions under which he/she decides to deal with it through self-medication, and the question of the connection between perception of a symptom and self-medication remains. On the other hand, many studies on the determinants of self-medication examine the effects of people's demographic, economic and social characteristics on the probability of the resort to self-medication, irrespective of symptoms (RAYNAUD, 2008). The mechanism by which the subject decides to cure his/her ailment by him/herself partly depends on a process of deciphering a bodily sign which ought not to be reduced to what leads him/her to resort to a doctor. Besides, although resort to the Internet in order to obtain information on symptoms and on drugs is an object of common interest in social sciences nowadays (AKRICH & MÉADEL, 2004; HARDEY, 2004), we lack observation of concrete practices in this regard.

To speak about the symptoms people identify as such and which they decide to self-medicate, is not to refute the concept of construction and to necessarily consider the symptom as an objective fact (in the sense that it is objectifiable by measurements, analyses or markers) to which the subject could simply react in a given way, and that he/she should merely be able to recognize or not. We must consider the process which makes a bodily sign acquire the status of a symptom in the subject's eyes, whether it is acknowledged by a health professional or not. On the other hand, to speak of construction does not imply that we consider the symptom to simply be the result of a subjective perception by the subject, as if it did not exist in itself, and as if it were only a fabrication or product of the subject's imagination. From the moment when he/she perceives what he/she considers to be a symptom, the latter has an objective existence, since it involves a social response, and therefore a social practice, namely self-medication. It is then more correct to speak both of *construction* and *identification* of symptoms. Anthropologically speaking it involves acknowledging that the symptom has a real existence, independent of its medical reality (which is in any case another type of cultural construction). The process of construction-identification must be considered as a whole since it implies that,

for the subject, the symptom exists in itself, at a given moment of his/her existence, and that this is what induces the act of choosing to medicalize the sign perceived.

In the framework of self-medication, it is the subject who is the author of the expertise; he/she is the one who translates the bodily sign into a symptom, even though he/she is caught between multiple social and cultural influences. But this operation cannot be reduced to the sole interpretation of illness. It amounts to determination, by the subject, of what must be brought into line with the norm, by means of a process which I will call "self-medicalisation". Indeed, whilst consulting a doctor and following up treatment might imply a possible reinterpretation of – or an adjustment to – the prescription, which supposes a self-evaluation of its relevance, self-medication involves more than this, as it generally includes self-examination and self-diagnosis as well, particularly when there has not been any previous recourse in relation to this symptom.

However, I do not support the distinction between *subjective symptoms* (referring to disorders perceived and reported by the patient) and *objective symptoms* (referring to disorders observed or noted by the doctor) commonly made by clinicians and elaborated within the framework of medical semiology - a difference which covers the distinction clinicians also make between soft data et hard data, referring to what patients feel and what doctors observe or measure (SEBEOK, 1994).

The reality of the perception of symptoms by patients makes them as objective as those seen by the doctor. From an anthropological perspective, subjective signs are objective phenomena, in so far as they exist in the life and the consciousness of individuals and actually generate social acts. Thus, a symptom has *an objective reality for the subject*. Such a formulation might appear to be an oxymoron, but it aims to assert the objective reality of a subjective phenomenon from the moment when it induces a social practice such as self-medication or even self-medicalisation.

Nor will I use the distinction between 'lay' and 'professional' perceptions usually employed by sociologists. Not only because the use of these notions would imply, as Good (1994) showed,

to put them into a hierarchical relationship, or because this distinction would refer to the idea that their differences of content necessarily imply radical differences between people (patients and health professionals) belonging to different worlds (BALCOU-DEBUSSCHE, 2006), but also because, on the one hand, this distinction involves adopting the medical perspective insofar as it qualifies a phenomenon according to how it is perceived by health professionals and defines it through the 'non-professional' and 'non-initiated' character of the knowledge on which it rests, and on the other hand, because these categories may overlap.

Between sign and symptom

In medical semiotics, the symptom is opposed to the sign. The words "symptom" and "sign" are used in different ways and are sometimes interchangeable from one author to another¹. For some authors, a symptom is one kind of sign. For Peirce (1978), for instance, the symptom is a 'subspecies' of sign, and only 'represents' something else (that is to say that it is in such a relation to something else that it is treated as if it were this other thing). But a clinical sign may be identified as the symptom of a disease only in reference to the code of medical semiology (POUCHAIN *et alii*, 1996). Therefore a sign becomes a symptom by means of its clinical interpretation; whilst for others it is the symptom which becomes a sign in the context of clinical speech. For Shands (1970), the symptom is felt by the patient (for instance: tiredness) and the sign is noted by the doctor (for instance: impairment). In the same way, for Foucault (1963), the symptom is the form in which the disease appears: "It is the intervention of a consciousness which transforms the symptom into a sign" (p. 92). Foucault notes that this operation, which transforms the symptom into a meaningful element, is achieved through comparison, recollection, recording of the frequencies, simultaneities or successions. The symptom

¹ For a thorough presentation of the meaning of symptom, see Sebeok (1994).

thus becomes a sign beneath a gaze that is “sensitive to difference, simultaneity or succession, and frequency”.

So, the very relationship between the words “sign” and “symptom” varies. This variety of uses appears even more when Sebeok (1994) considers “subjective symptoms” as what doctors confusingly call “signs” (p. 68). Yet, whatever the direction in which those terms are connected to describe this process (from sign to symptom or from symptom to sign), it is striking to see that it is only in the context of clinical speech that this transformation is supposed to be made. For Barthes (1972) for instance, a symptom becomes a sign only when it enters the context of clinical discourse, i.e. when this transformation is made by the doctor, and thus only by the mediation of language.

In fact, these varying views seem to relate to different ways of apprehending the term “sign”. We notice that sign is either seen as bodily sign, either as clinical sign, so that, depending on the authors, we have either: <sign → symptom> or <symptom → sign>. Yet this transformation can be made by the subject²; and this is what actually occurs when he/she decides to choose a given drug for a given symptom in his/her medicine cabinet. Therefore this transformation is achieved by an intellectual operation that is also present in the process of self-medication. However, for the subjects, these two schemes may co-exist, leading to the process: <Bodily sign → symptom → pathological sign>. Through the process of self-clinical examination and self-diagnosis achieved by the subject, the sign (as a bodily sign) is converted into a symptom, but the symptom is converted into a sign of something pathological and of the necessity to medicalise it – possibly via self-medicalisation – an identification which results from a social process. It is not certain, in this respect, despite the usefulness of semiotics to “help physicians complement the project of interpreting signs and symptoms into diagnoses” (NESSA, 1996), that semiotics really adds to our understanding of what makes a subject medicalise a body occurrence in the context of self-

² As Massé (1999) underlined in his study on psychological distress, before being a clinical sign, the symptom is a sign for the ill person and his close kin.

medication. What is relevant to the anthropological perspective is that the relationship between sign and symptom depends on the level under consideration: from the body level to the social level.

Symptom and self-medication

A great number of works on the relation between symptom and self-medication conclude that the main symptom that people try to alleviate or to cure is pain, using analgesics (AIACH & CÈBE, 1991; CSA/CECOP, 2007; BARTHE, 1990; BUCLIN & AMMON, 2001; MOLINA, 1988; STEUDLER F., 1999). Yet such a conclusion is not enough to understand the intellectual process surrounding the identification of symptoms, on which the answer the subject decides to give to it depends, from the discovery of a bodily sign to self-medication via self-examination and self-diagnosis.

SELF-CLINICAL EXAMINATION

Let's take the example of pain. The subject undertakes a clinical examination on him/herself, for example by palpating his/her body, looking for a reaction, for a pain occurring at the place of palpation, or to discover another symptom, with any new symptom discovered likely to become an additional proof of the existence of a pathology. Concomitantly with this self-clinical examination, the subject asks him/herself questions (following the example of the doctor): "Did I eat something different from what I usually eat?"; "Do I have worries at the moment or specific reasons to somatize?" etc).

It is worth noting the social dimension of a practice such as self-examination. The very conditions of its performance say something about people's relationships with their nearest and dearest. For example, just as some people hide their self-medication from their family (for example, Mrs. E. secretly takes hypnotics because she fears her mother would be worried if she found out that her daughter was having trouble sleeping), some people explore their bodies and question their symptoms, out of sight of their families. It is a question either of keeping the state

of one's body secret out of modesty (modesty that also sometimes stops the subject from consulting a doctor), or of not worrying one's relatives who, when learning the existence of the symptom, might push the subject into consulting a doctor. In this case, the place for examination might be in bed, in the bathroom or in the toilet, so in a private space, adapted to an intimate clinical investigation. On the other hand, it might be done openly, to attract the attention and the interest of one's close relations, the subject accompanying self-examination by a complaint or a verbalization, leading the close relations to take an interest in his/her state. But the purpose is not necessarily to benefit from "secondary gains" (as BRODWIN 1994 puts it, from what he calls the "social performance" of dramatically expressing one's pain and suffering from one's symptoms in the context of chronic illness with the aim of having one's tasks reduced – whether in the workplace or within the family), but, beyond compassion, to appeal for advice in order to know how to deal with one's symptom. The choice of the place where the clinical self-examination takes place has social consequences since, in the second case, the subject is no longer alone in facing his/her symptom, but calls for advice or collective decisions.

Self-examination also makes it possible to highlight what we might call "symptoms of good health", which are likely to balance or to refute morbid symptoms and to make the subject refrain from consulting a doctor or even from self-medicating: Mr. D., a computer engineer, had a stomach ache. He thought of taking intestinal powder. But after touching various spots on his body, he thought with anxiety it might be appendicitis. He then pressed the area above the appendix, but the pain did not increase on this spot. So he concluded that it couldn't be appendicitis and that his pain was nothing serious, probably the effect of digestive problems and decided to take spasmolytics (though the ailment didn't cease as we will see under). Therefore, during clinical self-examination, symptoms also affect the subject's cognitive

work through their absence, likely to make him/her modify his/her first assumption³.

FROM SELF-DIAGNOSIS TO SELF-MEDICATION

When the subject feels a pain, the meaning that he/she gives to it is likely to induce certain practices as regards self-medication. The pain first requires an interpretation before giving way to the pharmaceutical answer which self-medication represents. The subject tries to interpret his/her pain by relating it to the events of his/her present or recent life and to his/her past experience of pain, which will direct the way in which he/she chooses to suppress or to curb it. Anthropologists know that the translation of a bodily feeling into a symptom requiring care depends on the context in which the patient finds him/herself and on his/her story: what the patient has experienced, the information he/she has on the illness or ailment, what he/she identifies as a symptom, the perception he/she has of the way in which health professionals have dealt with the problem in the past, etc. (KLEINMAN, 1980; FAINZANG, 2000). But the point to be added here is that this translation (this process of constructing/identifying the symptom) is performative, because it mobilizes a system of norms characteristic of the subject and leads him/her to take a drug, on his/her own initiative. The subject devotes him/herself to an examination of the context in which the symptom appeared.

For example, Mrs. D. interprets a stomach ache as a pain caused by her imminent period because she is in a pre-menstrual period, whereas Mr. G interprets it as an intestinal disorder because he has just returned from a trip abroad and Miss. F. puts it down to a gastric pain, following a heavy meal she has just eaten at the restaurant. Or the subject may relate it to his/her nervousness, insofar as he/she is going to perform a social action which generates fear or emotion: public speaking or performance, medical examination, amorous meeting, exam, etc. The same

³ People readily associate the absence of a symptom to the absence of illness. The symptom is therefore the element *par excellence* which objectifies the ailment in subjects' eyes.

person might also attribute different meanings to the same pain, depending on when he/she has the experience.

This attribution will of course affect the responses he/she will give, as depending on the cases, the subject will take anti-spasmodics, analgesics, anti-inflammatories, intestinal antiseptics, or tranquillizers. Then, beyond the specific sensorial dimension of the symptom, when the medicine which has been taken proves ineffective, for example, the subject might be led to change his/her interpretation of the pain when the latter persists even though it should have ceased, or if it reappears – for instance, if the woman is no longer having her period, or when the social action involving emotion has been completed. For each interpretation, the response will be specific, and the management of the pain will be different.

For the subject, pain may be considered either as a symptom of something else, or as an ill in itself, which should be treated. Some try to cure it immediately by taking analgesics, whereas others resort to analgesics while taking other drugs considered being capable of curing the ailment of which the symptom is a sign, or while observing the evolution of the symptom (or of other symptoms which are likely to provide more information about the first one). Taking an anti-inflammatory to alleviate a pain formerly diagnosed by a medical doctor (for instance osteoarthritis) is not the same intellectual operation as taking analgesics for an unknown pain while observing whether or not the pain diminishes, and whether it is soon accompanied by other signs. Faced with a new pain, the subject will then have the choice between taking drugs (analgesics) to put an end to the pain or waiting to see how it will evolve and possibly awaiting the appearance of other signs in order to be able to make a diagnosis or to confirm the first diagnostic intuition.

The attribution of a meaning to a symptom is not a static process. People observe the development of their symptoms. When he feels a pain, Mr. D., mentioned above, tries to identify his symptoms and the way they develop or are accompanied by others. We have seen that when he had a stomach ache, he first thought he should take an intestinal powder, and that after excluding the hypothesis of appendicitis, he decided to take anti-spasmodic.

But, his intestinal transit was soon disturbed, leading to him no longer passing stools. He then decided to take a laxative. But as the pain went on, he thought it might be an intestinal occlusion and decided he should see a doctor. The doctor told him it was the stress which gave him colic, and prescribed tranquillizers. So whenever he feels this type of stomach ache, he now applies the same etiology and uses analgesics or tranquillizers.

People also indulge in certain kinds of experiment. For instance, Mrs. C. had an angina after several former episodes of pharyngitis. Each time, she was prescribed antibiotics, but the pharyngitis came up regularly. She then decided it was no use to take antibiotics again. She first took lozenges she had in her medicine cabinet at home, but without satisfying results. Concerned about taking into account the context in which this angina appeared, that of an “affective break out”, she decided that her angina was the result of somatization. One of her colleagues told her that a sore throat may be caused by intolerance to sugar. Mrs. C then decided “to do an experiment “. She bought a “big piece of chocolate” for herself and straight away felt an acute sore throat. She concluded that sugar maintains her repeated bouts of throat pains. “Sugar is the sweetness of life”, she explains, “it is difficult to accept having to deprive oneself of it, but I’ve managed!”, associating the fact of accepting to deprive herself of this sweetness with the necessity to accept her emotional disappointment. She then stopped taking both lozenges and antibiotics. Her experiment was intended to allow her to self-diagnose her pain and to test the relevance of the treatments, and induced another way of managing her symptom.

Identifying a pathological sign

The construction/identification of a symptom raises the fundamental question of the distinction between the normal and the pathological. For Canguilhem (1966), the judgment of what is pathological depends on who institutes the norm. Yet, in the case of self-medication, it is the subject who establishes his/her norm, a norm that will be juxtaposed with – or possibly superimposed on – that which is established by biomedical discourse or by the

pharmaceutical industry, or by his/her close circle and family, and therefore a norm in the construction of which the social environment (close kin, friends, colleagues, media, etc.) plays a part. For instance, Mrs. V. has had difficulties falling asleep since her husband left her. She tells her mother who gives her a box of 'Stilnox®', a hypnotic (International Nonproprietary Name: zolpidem) and suggests that she takes one every evening as she herself does to deal with her own insomnia. It is what Mrs. V. does, relying on her mother's experience. People also look for advice on the Internet, when confronted with a symptom they do not know. For instance, they can look for advice on discussion forums to help them to identify a symptom, its etiology, its level of gravity, as was the case for Mrs. F., who felt a very nasty bitter taste in her mouth and who decided to take anti-histaminic until she discovered on a forum on Internet that it was due to the consumption of certain kinds of pine nuts imported from China she had precisely eaten the day before, and that it would disappear after one week.

The operation is twofold since the person must first identify what he/she thinks to be pathological, then, consider whether this sign/symptom is a case in which self-medication is indicated. To examine at what point a bodily sign becomes a symptom (or a symptom becomes a sign of a pathological state) in the context of self-medication, is to examine at the same time the criteria that cause the sign to shift from the status of normal to the status of pathological and the criteria which cause the symptom to shift from the status of a sign to be dealt with (that is to say to be medicalized) to that of a sign to be dealt with *by oneself* (that is to say to be what I will call 'self-medicalized'). So, for the person concerned, it is no longer just a question of relying on the medical norm to define the pathological. In a situation of self-medication, a sign becomes pathological if it differs from that which the subject considers to be the norm of *his/her* body. For instance, the subject may recognize a perception as something he has already seen or perceived (on his/her body or on the body of someone else: of a close relation, in particular of one's child), the appearance of which may have been followed or preceded by another symptom, in a sequence which takes on a meaning. But it may also be the

first time he/she sees a given sign, to which he/she tries to give a meaning. Mrs. G. has a husky voice. She thinks that it is a sign of ageing and considers it to be normal. But she is somewhat bothered by her voice, finding it to be unpleasant, so she buys sweets that she can suck to soothe it. As the problem persists, she then thinks it is the result of a cold or pharyngitis and takes pharmaceutical syrups for the throat. It is the qualification of pathological which makes this bodily sign a symptom. But her voice remains husky until one day she realizes that people don't recognize her any longer on the phone. She will finally decide to consult a doctor because she fails to explain or to identify what is causing this bodily sign to which she has given the status of a symptom.

Alternative situations

Sometimes subjects treat their symptoms with self-medication when they do not find satisfactory solutions from doctors (FAINZANG, 2010). What is at stake here is the appraisal of one's competence *versus* a doctor's competence, or even as regards recognition of the pathological character of the symptom. It is a case of what doctors qualify as "functional disorders", that is to say symptoms not recognized as organic or physio-pathological (also called 'medically unexplained symptoms'; see Risor, 2010), a formula that patients often understand as a diplomatic way of telling them that there is nothing wrong, or when the subject has developed a personal knowledge about a specific ailment he/she has experienced. Mrs. A. decides to cure her headache by herself because it is not taken seriously by her doctor. She has what she calls "the 48-hour ailment", a very intense headache which appears three times a year, and which lasts 48 hours, and that she connects with her work ("In my case, it means that I am overloaded with work", she says). Although her doctor laughed when she told him about it, she considers her headache to be a real pathological entity, with always the same expression, intensity and duration, that she associates with her being overworked. So she decides that she should cure herself: "I know myself. I

know what I need", she says, and when it occurs, she takes anti-inflammatory pharmaceuticals around-the-clock.

Or, sometimes the subject takes a pharmaceutical after reading a leaflet and recognizing a symptom he/she thinks he/she has, without being necessarily, at that particular moment, in search of something to cure this symptom. Mrs. F. does some tidying up in her medicine cabinet in order to throw away what is out-of-date. Not remembering the indications of one drug which was long ago prescribed to her husband, she opens the package and consults the leaflet inside. Reading the instruction leaflet to see if it can be of any use and if she needs to keep it, she recognizes a symptom that she sometimes experiences (actually nausea) and says: "Oh, my! This is something I often have! I must take it next time I have my sea-sickness" (a term used to refer metaphorically to her nausea). This is the opposite process to that which consists in seeking a remedy for one's symptom, since here the encounter with the drug precedes the identification of the symptom and the search for some appropriate medicine.

The very designation of the ailment often refers to the symptom or to one of its characteristics. The subjects thus indulge in a kind of self-nosography, that is to say to a symptomatic designation they construct in reference to the bodily symptom itself (for instance: "the husky voice"), or to a characteristic of the symptom such as its duration (for instance the "48 hours ailment") or what it evokes metaphorically (the "sea-sickness").

On the whole, when examining concrete situations, it appears that the existing bond between identification of symptoms and self-medication is woven around at least four models:

An empirical model, where the symptom is familiar and where the subject considers him/herself as able to deal with it; its identification depends on experience, leading him/her to conclude that a consultation is useless.

A substitutive model: the subject does not necessarily know very much about the symptom, but his/her feeling that the doctor is incompetent to deal with this symptom leads him/her to choose self-medication, in particular when the symptom has already appeared before and has been the object of a previous

consultation, and is considered by the patient as not having received a satisfactory therapeutic answer from the doctor,

A moral model, i.e. concerning the field of good manners or of moral-social judgment: the symptom relates to a part of the body which is considered as having to be hidden (ex. hemorrhoids) or refers to an activity about which the subject fears the doctor's judgment (ex. sexual activity),

A cognitive model, when the symptom is not recognized by doctors or not associated to the identification of a disease, or when the subject has acquired personal, private, sometimes unshared knowledge of it.

An analytical model, that is to say a model where an analytical judgment is exerted: when the subject finds a personal explanation for his/her symptom which leads him/her to deal with it in a personal way (cf. Mrs. C. above).

Absolute and relative symptoms

According to Sebeok (1994), in a doctor's eyes, to a given symptom corresponds necessarily a meaning and consequently a specific disease. He writes in this regard: "a symptom is a compulsive, automatic, non-arbitrary sign, such that the signifier is coupled with the signified in the manner of a natural link" (p. 46). In fact, this may also be true in the framework of self-medication. Actually, although the same symptom may signify various illnesses and although the same illness may present different symptoms, a subject sometimes makes a bi-univocal connection between the two as regards his/her own case, on the pattern of medical semiotics, so that he/she automatically connects a given symptom to a given illness and thus infers a given diagnosis, in line with what Sebeok (1994) describes with regard to medical semiotic activity. It is the case with Mr. D. above who, from now on, decides his intestinal pains are the result of stress and are dealt with tranquillizers. But, as Umberto Eco (1992) underlined, the meaning of the sign is not univocal, as a symptom is always identified in relation to a precise context. Indeed, not only is this transformation (construction/identification) between sign and

symptom not the same from one person to another, but it is not necessarily the same for the same person from one moment of his life to another, as we have seen with Mrs. C., who changed both her interpretation and her way of dealing with her sore throat when a change occurred in her life. Therefore, whilst there might be an automatic relationship between sign and symptom, there are also symptoms that take on a specific meaning which is valid only for him or her, in a sort of idiosyncratic nosography, along the model of: "In my case, this means that".

Finally, for the subjects, there are what we might call symptoms with "absolute value" (where such signs necessarily have such values), but also symptoms with "relative value" (where such signs have a specific value which is valid only for him/her). Thus by contrast with the usual approach of therapeutic recourse in a given cultural setting that anthropologists study with reference to a collective norm expressing that of the prevailing medical system of thought, we here have a recourse to pharmaceuticals based on a norm that feeds simultaneously on the collective norm and on an individual norm, made up of the subject's experience and of the various influences exerted on him/her, which may result in people granting varying values to the same symptom.

Conclusion

The process of decoding a symptom is therefore at the intersection of the individual and collective levels. The interpretation of a symptom is both individual and collective, insofar as it is simultaneously typical of a cultural group or a social category, and specific to one subject. Although, as social sciences have shown (BARTHE, 1990), the appearance of a symptom can be perceived differently according to the social background of the subject, it would however be highly reductive to assimilate a subject to his sole social background, even when taking into account other socio-demographic variables such as age and sex. It would amount not only to neglecting the subject's personal history, but also to *unifying* his/her history as if it were invariable. A subject reacts differently to a symptom according to whether he/she has

already experienced that symptom before, whether he/she has had new information on the symptom, whether he/she knows a close relation who has already experienced it, whether he/she has consulted Internet on this matter, whether he/she has consulted a doctor for a similar symptom in the past, whether or not the symptom was explained, cured, followed by others, etc. In a way, at every moment of the subject's life, the context in which the symptom appears is different. So whilst symptoms are not arbitrary signs, they are not automatic signs either. They have a relative value which consists not only in the fact that they can have a given value for one given subject, distinct from what it is for another one, but also distinct from the value they can have at another moment of that subject's history. A symptom is then caught between the new conditions of its appearance and the idiosyncratic doctrines that people forge about it.

Whilst the opposition between subjective signs and objective signs may not mean anything to the self-medicating subject, on the other hand, as we have seen, there is a relevant distinction to be made between absolute symptoms and relative symptoms, i.e. between the value that a person attributes to a symptom as a result of his/her medical knowledge, socialization, health messages, doctor's explanations, pharmaceutical leaflets, etc., and the value he/she attributes to a symptom in its relation to him/herself, to his/her body, his/her story. The work of deciphering the symptom is situated at the crossroads between the individual and collective levels. The co-existence of symptoms with an absolute value and symptoms with a relative value results from the tension between the individual and the collective dimensions of the symptom deciphering work carried out within the framework of self-medication. This co-existence is what makes the process of construction/identification of symptoms by the subjects a true semiological process.

References

- AIACH, Pierre and CÈBE, Dominique (1991) *Expression des symptômes et conduites de maladie*. Paris: Inserm/Doin.
- AKRICH, Madeleine and MÉADEL, Cécile (2004) "Problématiser la question des usages", *Sciences sociales et santé* 22 (1) 5-20.
- ALONZO, Angelo A. (1984) "An illness behaviour paradigm: a conceptual exploration of a situational-adaptation perspective", *Social Science & Medicine* 19 (5) 499-510.
- BALCOU-DEBUSSCHE, Maryvette (2006) *L'éducation des malades chroniques. Une approche ethno-sociologique*. Paris: Editions des archives contemporaines.
- BARTHE, Jean-François (1990) "Connaissance profane des symptômes et recours thérapeutiques", *Revue française de sociologie* 31, 283-296.
- BARTHES, Roger (1972) "Sémiologie et médecine", In BASTIDE, Roger (ed.) *Les sciences de la folie*. Paris: Mouton, 37-46.
- BRODWIN, Paul E. (1994) "Symptoms and Social Performances: the case of Diane Reden", In DELVECCHIO GOOD, Mary-Jo, BRODWIN, Paul E., GOOD, Byron J. and KLEINMAN, Arthur (eds.) *Pain as human experience. An anthropological perspective*. Berkeley: University of California Press, 77-99.
- BUCLIN, Thierry et AMMON, Catherine (eds.) (2001) *L'automédication: pratique banale, motifs complexes*. Genève: Médecine et Hygiène (Cahiers Médico-Sociaux), 11-29.
- CANGUILHEM, Georges (1966) *Le normal et le pathologique*. Paris: PUF.
- CSA/CECOP (2007) "Les Français et l'automédication", enquête exclusive réalisée pour la Mutualité Française.
- DELVECCHIO GOOD, Mary-Jo, BRODWIN, Paul E., GOOD, Byron J., KLEINMAN, Arthur (eds.) (1994) *Pain as human experience. An anthropological perspective*. Berkeley: University of California Press.
- ECO, Umberto (1992) *La production des signes*. Paris: Le livre de Poche.
- FAINZANG, Sylvie (2000[1989]) *Of Malady and Misery. An Africanist Perspective of Illness in Europe*. Amsterdam: Het Spinhuis Publishers (Coll. Health, Culture & Society).

- FAINZANG, Sylvie (2010) "L'automédication, une pratique qui peut en cacher une autre", *Anthropologie et Sociétés* 34 (1) 115-133.
- FOUCAULT, Michel. (1963) *Naissance de la Clinique. Une archéologie du regard médical*. Paris: PUF.
- GOOD, Byron J. and GOOD, Mary-Jo (1981) "The meaning of symptoms: a cultural hermeneutic model for clinical practice", In EISENBERG, Leon and KLEINMAN, Arthur (eds.) *The relevance of social science for medicine*. London: D. Reidel Publishing Company.
- GOOD, Byron J. (1994) *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- HARDEY, Michael (2004) "Internet et société: reconfigurations du patient et de la médecine?" *Sciences sociales et santé* 22 (1) 5-20.
- HAY, Cameron (2008) "Reading Sensations: Understanding the Process of Distinguishing 'Fine' from 'Sick'" *Transcultural Psychiatry*, 45 (2) 198-229.
- KLEINMAN, Arthur (1980) *Patients and Healers in the Context of Culture*. Berkeley: University of California Press.
- MARTINEZ-HERNÁEZ, Angel (2000) *What's Behind the Symptom? On Psychiatric Observation and Anthropological Understanding*. Amsterdam: Harwood Academic Publishers.
- MASSÉ, Raymond (1999) "Les conditions d'une anthropologie sémiotique de la détresse psychologique", *Recherche sémiotique/ Semiotic Inquiry* 19 (1) 39-62.
- MOLINA, Nelly (1988) *L'auto-médication*. Paris: PUF (Coll: Les champs de la santé).
- NESSA, John (1996) "About signs and symptoms: Can semiotics expand the view of clinical medicine?", *Theoretical Medicine and Bioethics* 17 (4) 363-377.
- PEIRCE, Charles S. (1978) *Écrits sur le signe*. Paris: Seuil.
- POUCHAIN, Denis, ATTALI, Claude, de BUTLER, Jean, CLÉMENT, Guy, GAY, Bernard, MOLINA, Joëlle, OLOMBEL, Patrick, ROUY, Jean-Loup (1996) *Médecine générale. Concepts et pratique*. Paris: Masson.

- RAYNAUD, Denis (2008) "Les déterminants du recours à l'automédication" *Revue française des affaires sociales* 62 (1) 81-94.
- RISOR, Mette Bech (2010) "Healing and recovery as a social process among patients with medically unexplained symptoms (MUS)", In: FAINZANG, Sylvie, HEM, Hans Einar and RISOR, Mette Bech (eds.) *The Taste for knowledge: Medical Anthropology Facing Medical Realities*. Copenhagen: Aarhus University Press, 133-149.
- SAND ANDERSEN, Rikke (2010) "Anthropological perspectives on the biomedically defined problem of 'patient delay'", In: FAINZANG Sylvie, HEM, Hans Einar and RISOR, Mette Bech (eds.) *The Taste for knowledge: Medical Anthropology Facing Medical Realities*. Copenhagen: Aarhus University Press, 57-68.
- SEBEOK, Thomas A. (1994 [1921]) *Signs. An introduction to Semiotics*. Toronto/Buffalo/London: University of Toronto Press.
- SHANDS, Harley C. (1970) *Semiotic Approaches to Psychiatry*. The Hague: Mouton.
- STEUDLER, François (1999) "Aspects sociologiques de l'automédication", In QUENEAU, Patrick (ed.) *Automédication, autoprescription, autoconsommation* (2^{ème} colloque de l'Apnet). Paris: John Libbey, 23-32.

THE ALLERGY EPIDEMIC, OR WHEN MEDICALISATION IS BOTTOM-UP

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Allergy has been defined as the xx century epidemic and epidemiologists estimate that in 2015, 50% of the population will suffer from an allergy (BOSELEY, 2004). Allergic reactions exist since always as physiological response but only in the last century allergy has been socially constructed as a *scientific object*: since Clemens von Pirquet – an Austrian paediatrician – has named this condition with a specific term – allergy – , there has been a flourishing of social constructs (debates, a scientific community, laboratories, departments, books, journals, diverse therapies, etc...). Their existence has granted allergy of an ontological status: allergy thus appears as a real disease and a scientific¹ entity and they have promoted the dissemination of knowledge on this condition. Together with this biomedical apparatus, a public audience has also developed: patients, a specific market and dedicated media communication. Increasingly people declare to suffer from an allergy even if they have not been tested (or if they were tested negative) and their symptoms are varied, spanning from impotence to being overweight (ALTMAN and CHIARAMONTE, 1996).

To reflect this situation, this paper analyses ‘allergy’ as employed in everyday interactions: a wide cultural category with ambiguous contours. Allergy is a wide term referring to a specific biomedical category, but it also portrays a general cultural phenomenon. In biomedicine the official classification has been proposed in 1963 by two English immunologists, Philip Gell and Robin Coombs (1963), who classified diverse hypersensitivity disorders taking

¹ For discussion about the existence of scientific objects see, for example, LATOUR, 2000 and DASTON, 2000.

into account immunological processes and not only clinical symptoms. They outlined four types of hypersensitivity reactions but, in practice, among allergologists the tendency (even if local and national variations exist) is to solely consider the first type of reactions, limiting the definition of allergy to reactions mediated by a specific antibody known as IgE². Alternatively, we might have decided to analyse a specific kind of allergy according to affected organs (nose, eyes, airways or systemic) or in relation to the triggering substance (food, dust, pollen, latex, mites, pharmaceuticals, etc...) or even taking into consideration the triggering process (contact, breathing, eating) or special kind of allergies as asthma. Given the indeterminacy of this situation and acknowledging that allergy has created a cultural domain of its own, this research aims to go beyond arbitrary categorisation trying to understand what allergy means for people in its current usage that often exceed symptoms, organs and immunological processes.

The traditional view on medicalization assumes that the biomedical domain influences significantly the public opinion regarding the knowledge of the causes of a disease and its treatment, so promoting and concretely 'creating' sickness (ILLICH, 1977). This paper aims to show that, in the case of allergy, the interaction between the biomedical domain and other public arena in the creation of a new biomedical entity is not so univocal, rather complex.

Methodology

This paper derives from ethnographic research undertaken between 2004 and 2008 in north eastern Italy, in which I focus on how diverse agents (patients and doctors) make sense of allergies and their diverse treatments. The research involved observations

² Immunoglobulin E (IgE) is a class of antibody that has only been found in mammals. Apart of playing an important role in allergy (type 1 hypersensitivity) it is implicated in responses to most parasitic worms.

of the treatment of allergy in a specialist unit of a public hospital in a medium-size city.

In the Unit, I established the biomedical perspective through conducting four semi-structured interviews, one focus group with four nurses, collecting various informational material produced for patients, and analysing the internal guidelines concerning diagnostic techniques and treatment. Daily, for a period of about three months, I observed and recorded doctor-patient interactions, and attended and video-recorded consultations and diagnostic sessions. During this time I also conducted semi-structured interviews with 28 patients, identified to allow variation in age, gender and ethnicity and in reported symptoms, regardless of their diagnosis outcome. Subsequent interviews were carried out with 16 patients who agreed to meet me again.

Twelve patients used or were using alternative medicine, and they referred me to thirteen practitioners practising alternative medicine. I was able to contact twelve of these, all of who agreed to an interview. I identified and interviewed three additional practitioners practising alternative medicine. Alternative approaches included homeopathy, iridology, pranotherapy, acupuncture, chiropractic, ayurveda, psychosomatic medicine and, in four cases, mixed approaches. Nine practitioners practising alternative medicine introduced me to patients suffering from allergic symptoms; and they were also interviewed in private or public sites. I conducted subsequent interviews with three of these respondents. Interviews were transcribed verbatim and fieldnotes were analyzed thematically, with analytic categories emerging to inform the development of further coding variables.

Biomedicine vs Patients: Two Opposed Paradigms

At the beginning of the xx century at the London's St. Mary Hospital allergy was strongly promoted: what was considered to be an allergic disease was treated by a team of young and successful immunologists (in particular John Freeman and Leonard Noon), coordinated by Sir Almroth Wright. To give an idea of the great success of this promotion campaign, enough is to say that in

1952 they conducted about 7500 consultations for hay fever and 4880 for other allergic symptoms (JACKSON, 2006); these numbers overcome lengthily the consultations for contagious illness recorded during the same year. The main therapy proposed at St. Mary was immunotherapy, which might be superficially described as a light vaccine therapy, promoted as being effective in curing diverse idiosyncratic symptoms (JACKSON, 2001b; 2003).

More or less a century later, an observer entering in an allergology department can detect a completely different situation: strong tension exists between patients and doctors because their intentions and meanings are not in harmony. Only a small percentage of the high number of patients who entered the department thinking to be allergic are tested positive by biomedical tests and only few of them are admitted to be treated as allergic. The rest of people are not accepted as allergic and their complaints remain without explanation.

Patients find themselves in an uncomfortable situation: many are sure to be allergic and they need an explanation; they need to give a name to their problems. After being rejected by the allergologist, usually people undertake a long and intricate therapeutic wandering: the gastroenterologist, the lung specialist, the psychologist, etc... Worse of all, often this therapeutic pilgrimage terminates without a concrete solution to the problem. Maria is an old woman desperately affected by various symptoms which do not permit her to live a normal life. Her biomedical trajectory shows a similar pattern with that of many other allergic people:

They told me I am fine and they sent me to many doctors. Eh, yes, they sent me everywhere and I even do not remember anymore where the hell I went. They sent me to the one [doctor] of the nose: he told me I am fine. I was there three times and last time they even put a little hose to make a deeper examination and nothing: they told me I am fine and they sent me to the one [doctor] of the tongue... the... the... stomatologist. I went there about ten days ago and he, too, told me 'Mrs, you are absolutely fine'. Now I went to all these doctors and they all told me that I am fine. I can partly understand,

some people maybe rig, I do not know... there is the mentally ill, but I know to have symptoms and I simply try to discover the cause.³

On the other side of the 'game' there are allergologists, who, too, face a heavy situation: waiting lists are long, patients to visit are many and in most cases doctors have to repeat the same discourse to them, striving to convince their patients that their symptoms are something else, but surely not allergy. Dt T. expresses his discomfort with this situation:

One have to define boarders: to define an allergic pathology clinic evidences are not enough. You cannot say that a person is allergic because he has symptoms which would suggest allergy. You need to test a specific allergic mechanism: according to the definition, the allergic mechanism has antibodies which are IgE. If you can demonstrate that this mechanism is at work, you can say that the patient is allergic. [...] Unfortunately in most cases you encounter people who are not allergic. Now food intolerance is trendy, or general practitioners are not able to properly address to the right specialist, so you might encounter people with symptoms but those have nothing to do with allergy but they are in your studio and you have to make the anamnesis... you would wish to say 'look, you have mistaken door!', ah, ah [he laughs] but you cannot do it. You cannot select patients, this is the problem. That means that everything arrives to you and very often, even before to make tests, you already know it is not useful [they are not allergic]... this is the depressing side of my job.

The disagreement between patients and allergologists is also reflected by the causal explanations offered by both parties. According to almost all patients environmental pollution⁴ is the

³ All interviews are originally in Italian and they have been translated into English by the author. The same applies to quotations of authors whose work has been originally published in a language different from English (reported in bibliography).

⁴ During MAAH (Medical Anthropology at Home) conference 2010 [<http://www.vjf.cnrs.fr/maah-france/>], Anne-Lise Middelthon observed that in Norway people would be more likely to refer to ingredients contained in food (as gluten and allergens) as their main fear instead than environmental pollution. Indeed, we cannot conclusively say that in every Western country allergies are perceived in relation to environmental pollution and further work is required to gain a more complete understanding of the context-relate variations, our findings indicate that this interpretation adheres to the specific

main cause of allergy. For example, Ivo is a young man who experiences tiresome skin reactions when he gets in touch with diverse substances and according to him this is caused by the presence of too many artificial materials in the environment: '...there's only plastic around... I cannot touch anymore freely around, I get swollen and red skin touching too many things. I am getting desperate [...] It's all a big garbage of plastic...'. Gina, instead, is a woman in her '40s who accuse violent reactions to pharmaceuticals. She, too, thinks that allergies are caused by environmental pollution:

Because there are too many noxious substances also in the environment, in the car... on the road with all that petrol burning... I don't think it is properly healthy. For the most I think it is caused by industry... all those chemicals... all those preservatives, additives, colouring agents, all those things... probably the body has to... it has big difficulties to adapt at... at assimilating all that, I think.

Allergologists consider this interpretation just a ridicule legend: according to them pollution doesn't matter at all in allergic diseases (VON MUTIUS, 1992; WARDLAW, 1995). Dr S. words give an humorous example of how biomedicine tends to reject lay explanations of allergy with put in place environmental pollution:

I might even say that they [allergies] are linked to... I mean... to... to the number of existing television channels. It is the same logic, I mean, it is the same kind of observation. Since the relationship between allergy and pollution has never been demonstrated, they are just two things that are simultaneously increased. I might make similar comparison, for example: until 30 years ago there were three television channels, now they are 30... maybe the television is the cause of the increase in allergies?!... or... Another: the fact that we make less children! I mean...yes, it could be that, because we make less children!... Or obesity?! Now people are more overweight than before! I am making these kind of comparisons to show that it is very

context of this research (Italy). At the same time she recognised that the Norwegian case is just another version of the same argument: in discourses on allergy pollution represents a fundamental anthropological category able to make sense of alternative causal explanations.

easy to find connections with... with anything. On the other hand, allergy has always existed, even 100 years ago when there was no smog. 100 years ago... 1000 years ago!

Two explicative paradigms oppose. For both parties – allergologists and patients – allergy is a sickness strictly connected with modernization and industrialization, but each party gives a different meaning to this connection. According to public opinion these factors affects the rate of allergy because they cause environmental degradation. Instead, according to widely accepted biomedical hypothesis allergy and modernisation are linked in a different way: the increased application of high hygienic standards prevents the immune system to ‘train’ and to accomplish its tasks in a regular way (STRACHAN, 1989; 1996). This situation is the cause of the immune system’s inability to perform correctly: it might burst in uncontrolled reactions against harmless substances, as in the case of allergy.

Given these premises the questions are: Why so many people are convinced to be allergic even if not tested? Why do they rely more to self-diagnosis than to biomedicine? Why has biomedicine moved from a promotional to a strictly selective attitude? In the further lines I will try to answer to these questions, thus highlighting the complexity of medicalisation processes, which lie at the crossroad of local and global articulations.

Cinderella Subject

In public discourse the word ‘allergy’ refers variously to diverse idiopathic conditions and it is even employed with metaphorical sense, so widening its use. As the historian Mark Jackson alerts us: ‘In the late twentieth century, in addition to being allergic to all manner of environmental stimuli, people could be allergic to work, allergic to Mondays, or allergic to their mothers-in-law’ (JACKSON, 2001a: 1668). This broadening of the cultural domain created by discourses about allergies finds a symmetrical opposed movement in biomedicine, in which the tendency has increasingly been to narrow the applicability of the term. Orthodox approaches

in allergology use the term exclusively referring to tested immunological reactions of a specific kind (IgE reaction). Since its creation, the use of the term 'allergy' and its theoretical foundations were hardly contested⁵; still now a shared international standard for defining allergy and an effective treatment is lacking. The main debate is whether allergy should include any form of modified biological reaction or only of immunological kind (KAY, 2006).

This situation has represented an ideal condition for a massive colonization of allergology by alternative medicine. The discipline has been defined more than once by its practitioners as a 'Cinderella subject', middle land between orthodox biomedicine and heterodox medicines. Frequently people decide to consult CAM⁶ (BIELORY, 2002; ERNST, 1998; SCHAEFER, 2004; SCHAEFER *et alii*, 2002) and even if in many cases improvements of symptoms might appear a chimera, often in these contexts patients receive positive feedbacks about their pre-assumption and interpretations of their condition because allergy – both as term and wide concept – is easily accepted by alternative practitioners.

Heterodox approaches are many and they might include alternative practitioners but also biomedical doctors practicing any kind of ecologic, environmental or alternative medicine. Unless specificities, what they all have in common is the great consideration given to environmental factors and an ecologic-holistic view on health and illness, which is contrasting with the reductionism of orthodox biomedicine. Non orthodox approaches legitimise a wide use of the concept linked to 'allergy', attempting to treat allergic symptoms either involving immunological reactions or not. Nowadays alternative medicines play a fundamental role in medicalisation, provoking what has been called as a 'medicalisation profane' (FASSIN, 1998). This

⁵ Since the start of allergology there was a clash between the clinic and the theory, because on one hand practitioners needed a term and a therapy to label idiosyncratic conditions but, on the other hand, researchers were contesting a unified theoretical frame of explanation for different reactions of hypersensitivity (offered by the concept of allergy).

⁶ Complementary and alternative medicine.

problem is well-known by allergologists as Dr V., who might be defined as an 'orthodox allergologist':

Then there is a problem of...psychological and commercial kind, let's say, ridden by not-specialist journals because now any magazine speaks about this... light medicine, alternative medicine, tests for intolerance, used to justify the most diverse symptoms, from tiredness to constipation to headache, etc, etc... Thus, let's say, all is...this increase in allergy rates is blown up.

If these approaches record great success, it is also because they echo the particular cultural climate increasingly resonating in Western countries in last decades.

Pollution. An Embodied Fundamentalism

As described above, people generally perceive allergy as caused by increased pollution of soil, air, food, water and by existence of pollutants in everything we touch and use in modern life, despite biomedical disvalue for explanation. Since the '60s, environmental degradation become a felt problem for the public and it started to appear in the political agenda of many Western countries (McCORMICK, 1989). Pollution has been ever more used as a viable explanation for many negative situations or conditions⁷. Illness often works as a language to express the person's conflicting relationship to society, whether in its industrial, economical, ecological or political expressions (FAINZANG, 2000). Allergy is employed by people as proper metaphor able to convey the both sensible and conceptual meaning of intolerance and rejection of the world as it is now, a world become too distant from human

⁷ It is important to stress here that the examined question is not whether environmental crisis is real or not, instead is its interpretation. The environmental movement includes people all speaking about the environment but with different political and economical interests because environmental problems have favoured the creation of a powerful coalition in which everyone aims to satisfy its own goal utilizing a commune vocabulary (HAJER, 1995; MILTON, 1993; YEARLEY, 1996). Eder describes environmentalism as a frame which is used to convey new meanings (1996).

sustainability and appreciation. Pollution, in discourses referred to allergy, appears as a totem for feelings of diffused negativity, originating from the perception that the world is getting worse and worse. In our research all the interviewees⁸ reported pollution as the main cause for their allergies. Anytime there is consensus criticism have to awaken.

Indeed, Mary Douglas (1966; 1975; 1985; DOUGLAS and WILDAVSKY, 1982) has previously observed that pollution is not just a matter of fact, it is also a cultural construction to indicate what is good and morally acceptable and what is bad and deplorable. Defining some portion of reality as 'polluted' and others as 'pure' societies support -both theoretically and empirically- their own moral cosmology. Humans have always required to be guided by norms in their exchanges with the outside world and the body plays a critical role in this process, being the phenomenological entity which first enters in contact with the outside world. The body is able to store and to display knowledge of embodied kind and the culturally-mediated concept of pollution acts significantly on its performances. In the case of allergy this is well exemplified by a couple of old ethnographic cases which precisely deal with allergic reactions⁹: in the '30s Sir Peter Henry Buck, an anthropologist from New Zealand, noted that in certain parts of Polynesia the appearance of skin rash was considered as a punishment for having consumed the meat of the own totemic animal (BUCK, 1932). Similarly, in the '50s, Ann and Jack Fisher, together with the colleague Frank Mahony, reported how people in Ponapean Island¹⁰ were affected by strong symptoms, similar to what we call 'allergy', when violating their totem by eating its meat (FISHER *et alii*, 1959). In contemporary Western countries totems are not anymore in use but a same circumspection in regulating exchanges between the individual self and the outside environment seems to be at work, even if with some differences.

⁸ All unless one, a chemist.

⁹ For an extended review see Raffaeta', 2006.

¹⁰ One of the Caroline Islands.

In past times individual and community purity was defended by social directives and by religious imperatives. Nowadays, instead, in modern democracies the individual is the sole in charge of her/his destiny and she/he has to carry the entire weight of this responsibility which reflects in great attention paid to the body. It is less and less considered as a given but it has to be 'reflexively mobilized' (GIDDENS, 1991: 723), as an artwork or a simulacra which need to be carefully managed and maintained. Never as much as today the body is at the core of individual and collective preoccupations as medium of individual expression: 'More people can think at themselves, more they are owner of their bodies and more identity is put in question' (EHRENBERG, 1995: 306). The individualism of modern times, which – among other things – expresses in a self-retreat of the individual within his own physical and emotional borders, causes an imbalance in the relationship between the self and the environment. This relationship cannot be a free flux of exchanges between the self and what stays outside it. The self is now magnified and it requires great care and attention in order to be preserved in its purity and defended by the assaults of the outside environment. Great anxiety generates in defending and protecting individual's borders and this is well mirrored by the ritualized practices displayed daily by allergic people to avoid the contact with diverse substances.

We shall argue that one of the main reasons why allergy result to be a successful conceptual category is because its metaphorical meaning matches well the general emphasis given to the protection of the individual sphere and of its purity. When speaking about pollution, in reality people seem to reinforce and bodily support this cultural framework. Historians Mark Jackson (2006) and Kathryn Waite (1995) remember us that, since the XIX century allergy was a desirable disease because it was associated with education and civilisation and to be allergic was a clear sign of a higher level of evolution.

To better clarify this concept we purpose to trace a parallelism between a well-researched topic as dietary restriction and allergy. Diets and allergies are different phenomena but they have in common is that both clearly indicate what is good to eat and what is to be avoided. According to Deborah Lupton the

contemporary fascination with diets, gastronomic fads and bio-foods appears as a substitute – more or less precarious – of norms traditionally imposed: ‘Where once imperatives around foods may have originated from primarily the constraints of seasons, availability and religious rules, contemporary restrictions over diet are imposed via internal constraints’ (1996: 74). Similarly Fischler (1988: 948) speaks of a state of ‘gastro-anomy’ in which ‘private symbolisms’ might be concretised in new forms which try to substitute older regulations which were giving order and consistency to reality. The history of Sara offers a good example of how allergies and diets are linked by a similar logic. Sara is a young woman a bit over weight; she went to an alternative practitioner who identified diverse foods to which she resulted intolerant¹¹ and now she declares to loose much weight following a specific diet which eliminate some foods from her meals. At the conclusion of our encounter she says: ‘Now I am in peace, I have understood what I can eat and what I have to avoid. All my life is now easier.’ As the words of Sara shows, narrations of allergy and diets often overlaps in the attempt to render easier the difficult task of deciphering the world. According to a binary-coded logic, to underline some substances as polluted and unhealthy is an operation to legitimately render other substances healthy and beneficial. The awareness of the continuous, incontrovertible and unstoppable contamination of what we eat, touch, drink and breath, reclaims the identification of a safe oasis, as in the words of Lupton (1999: 92):

the continual opposition of ‘processed/artificial’ and ‘natural’ foods is a response to uncertainty. If we can believe that a food is ‘natural’, then we feel better about eating it. In the context of a climate of risk and uncertainty, being able to hold on to such binary oppositions and their moral associations makes it easier to live one’s everyday life.

Substitutes to older regulations are many and they can vary, and if they are not supported by certain conditions, they can easily

¹¹ Sara used both the term ‘allergy’ and ‘intolerance’ to describe her situation. This is a common attitude and another example of the viscosity of the term.

degenerate in fundamentalisms. Allergy might be considered one of those substitutes, it is an embodied fundamentalism: people suffering from an allergy have to avoid to eat some food, or to enter in contact with certain places or substances, they can reorder daily life and create new practices, routines, meanings, reinventing the personal history according to a stable order which excludes doubt and risk. The case of Arturo is a brilliant example of this: he is a healthy, young man who desire to be tested for allergy just to exclude uncertainty:

Nothing happened to me. It is just a small mania: to see if I am allergic to something. I was bringing here [hospital, department of allergology] my daughter and so I have decided to do it [*test*] too. I have asked to my doctor and he told me 'ok'. I want to do it, I do not know...maybe they find an allergy to something...[*he laughs*] with all this pollution it might be likely. Thus, I will not eat that food anymore or I can prevent some disease or simply to feel stronger and better.

With the strengthening in recent times of environmental discourses into the public perception of diseases, allergy can be seen as a way of performing a precarious attempt of control over an environment which appears increasingly distant from an appropriate human and sensible appraisal.

Conclusion: What medicalization means nowadays

Initially the idea of allergy has been strongly promoted in clinical settings by biomedicine, in close collaboration with pharmaceutical industries. For example, Almroth Wright at London St. Mary's Hospital could finance much research on allergic diseases and other minor immunological syndromes thanks to a contract signed in 1908 with the north-American pharmaceutical industry, the *Parke, Davis & Company*, for the production of vaccines. In the USA Karl Koessler and Robert Cooke (who previously worked with Wright at St. Mary) signed contracts with other pharmaceutical companies as *Lederle & Abott Laboratoires* and similar things happened in Italy:

In the '70s Dr X opened an analysis clinic centre also with allergy tests, where in reality testing was done by neo-undergraduate people with the command to prescribe as many as vaccines as possible. But he was very famous in Italy, so, in reality, he has become millionaire. With an illegal activity, that means vaccines were prescribed by the same producer... eh, eh, eh... I [he laughs], the famous clinical analysis at the X style have been remained famous for many years. I do not know if the centre still exist... I think that now Dr X is an entrepreneur: he makes only vaccines and stop. But at that time he was an allergologist, or pseudo, because his activity was to employ neo-undergraduate people who prescribed a mile a minute vaccines for all and more. [...] Also Dr Z, famous paediatrician of C, has prescribed for years English vaccines which are a fraud because they are not antiallergenic extracts, they were those for bacteria, that means things without any sense. Consider that nowadays he doesn't prescribe that kind of vaccines but he is the owner of a company that produces mattress and pillow covers, and I do not think it is very compatible with his activity as doctor... and, fatality, all those pass by his ambulatory, most of them, goodness know, are allergic to mites. Then we see them and they are not allergic... many of them. Dr F.

In addition, with the creation of antihistamines, the market of anti-allergen products become very prominent and right now every pharmaceutical company counts an anti-allergic drug among its ten best sellers (JACKSON, 2006; MITMAN, 2003). The promotion of allergy accelerated when, in 1967 Ishizaka identified the antibody peculiar to allergic reactions (IgE) (ISHIZAKA and ISHIZAKA, 1967) because this event contributed to legitimise allergy as a real, specific pathology and to refine its testing methodologies: since 1978 the WHO initiated a promotion campaign of allergy (JACKSON, 2006: 111), considered as a problem of public health and thus, not surprisingly, in the '80s the WHO stated that between the '60s and the '90s allergic disease doubled (WHO, 1986).

In the midst of these economic and political processes allergologists have soon lost governance and sovereignty over the semantic range of discourses on allergy, which have easily slipped away from their hands to the public. The concept of allergy has been increasingly employed as a tool, as an efficient symbolic category to express new social and cultural tendencies prompted into the public arena by alternative medicines and global environmental discourses, which well adapt to contemporary marked individualism and increased secularisation. People are not just passive recipient of 'what the doctor say', rather they

elaborate scientific objects according to their world views. People may manipulate scientific knowledge according to their every day life experiences affected by global discourse, creating new meanings out of disciplinary concepts. The public may use scientific categories, as allergy, to express attitudes that only metaphorically recall the scientific one.

What can be learned from above is that the process of medicalisation includes different elements, often difficult to separate: the proclamation of new theories, the availability of new treatment and the development of social and cultural attitudes. All these aspects together, and not in isolation, assure a successful medicalisation of a given condition¹². Because of this complexity, the actors involved in the process of medicalisation are often multiple: doctors, pharmaceutical companies, alternative practitioners, patients. Their perspective and interests may be different and often contradictory and this heterogeneity leads to cast doubts over the utility of the same concept of medicalisation; it risks to appear an all-purpose concept.

I argue that the idea of medicalisation still shed light on specific dimensions. First of all it shows that a negative judgment over a given condition has been introduced, thus legitimating intervention and refusing diverse perspectives which may consider it as a normal or an healthy state. More importantly, the concept of medicalisation illustrates an agreement within a group or between diverse groups (doctors, pharmaceutical companies, alternative practitioners, patients) in recognising the human condition in terms of health and illness, attributing a central role to the body¹³. This is not a nuance, but is a central attitude able to determine how people in a given time and space interact with each other and with their environments and how they organise their culture and make it meaningful. As recent works illustrate (NOVAS and

¹² A famous example is masturbation, that from the beginning of the 18th century until the early 20th century was medicalised, while now is celebrated as an healthy practice (LAQUEUR, 2003).

¹³ The body remain a central actor also for alternative medicine, even if its definition may be different from biomedicine (e.g., negation of the body-mind divide and recognition of social determinants of health).

ROSE, 2005; PETRYNA, 2002; RABINOW, 1996) citizenship and sociality are increasingly defined in biological terms; health has become a negotiated realm of entitlement. This paper has taken allergy as a meaningful example to focus on patients' shift from passive to active actors, reflecting on the causes of this move through an interpretative approach. More research is needed to explore from different point of views this increased centrality given to health and the body in human interactions.

References

- ALTMAN, Dary R. and CHIARAMONTE, Laurence T. (1996) "Public perception of food allergy", *Journal of Allergy and Clinical Immunology* 97 (6) 1247-1251.
- BIELORY, Leonard (2002) "Complementary and alternative medicine population based studies: a growing focus on allergy and asthma", *Allergy* 57 (8) 655-658.
- BOSELEY, Sarah (2004) "The allergic epidemic", *The Guardian*: 1.
- BUCK, Peter Henry (1932) "Ethnology of Manihiki and Rakahanga", *Bishop Museum Bulletin* 99.
- DASTON, Lorraine (ed.) (2000) *Biographies of scientific objects*. Chicago: University Chicago Press.
- DOUGLAS, Mary. (1966) *Purity and Danger. An analysis of the Concepts of Pollution and Taboo*. London: Routledge & Kegan Paul.
- DOUGLAS, Mary (1975) "Environments at risk". In DOUGLAS, Mary, (ed.) *Implicit meanings*. London: Routledge.
- DOUGLAS, Mary (1985) *Risk Acceptability According to the Social Sciences*. London: Routledge.
- DOUGLAS, Mary & WILDAVSKY, Aaron (1982) *Risk and Culture. An Essay on the Selection of Technological and Environmental Dangers*. Berkeley: University of California Press.
- EDER, Klaus (1996) "The Institutionalisation of Environmentalism: Ecological Discourse and the Second Transformation of the Public Sphere". In SZERSZYNSKI, S. Lash, and WYNNE, B. (eds.) *Risk, Environment & Modernity. Towards a New Ecology*. London: Sage.

- EHRENBERG, Alain (1995) *L'individu incertain*. Paris: Calmann-Lévy.
- ERNT, Edzard (1998) "Complementary therapies for asthma: what patients use", *Journal of Asthma* 35 667-671.
- FAINZANG, Sylvie (2000) *Of Malady and Misery. An Africanist Perspective of Illness in Europe*. Amsterdam: Het Spinhuis Publishers.
- FASSIN, Didier (1998) "Avant-propos. Les politiques de la médicalisation". In AÏACH, Pierre and DELANOE, Daniel, *L'ère de la médicalisation. Ecce homo sanitas*. Paris: Anthropos.
- FISCHER, Jack, FISCHER, Ann, MAHONY, Frank (1959) "Totemism and Allergy", *International Journal of Social Psychiatry* 5 33-44.
- FISCHLER, Claude (1988) "Food, Self and Identity", *Social Science Information* 27 2 275-92.
- GELL, Philip G. H. and COOMBS, Robin R. A. (1963) *Clinical aspects of Immunology*. Oxford: Blackwell.
- GIDDENS, Anthony (1991) *Modernity and Self-Identity*. Cambridge: Polity Press.
- HAJER, Marteen A. (1995) *The Politics of Environmental Discourse. Ecological Modernization and the Policy Process*. Oxford: Clarendon Press.
- ILlich, Ivan (1977) *Medical Nemesis. The Expropriation of Health*. London: Calders and Boyer.
- ISHIZAKA, Kimishige, ISHIZAKA, Teruko (1967) "Identification of gamma-E antibodies as a carrier of reaginic activity", *Journal of Immunology* 99 1187-1198.
- JACKSON, Mark (2001a) "Allergy: the making of a modern plague", *Clinical and experimental allergy* 31 1665-1671.
- JACKSON, Mark (2001b) "Between scepticism and wild enthusiasm: the chequered history of allergen immunotherapy in Britain". In MOULIN, Anne Marie and CAMBROSIO, Alberto *Singular Selves. Historical Issues and Contemporary Debates in Immunology*. Amsterdam: Elsevier.
- JACKSON, Mark (2003) "John Freeman, hay fever and the origins of clinical allergy in Britain, 1900-1950", *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 34 (3) 473-490.

- JACKSON, Mark (2006) *Allergy: The History of a Modern Malady*. London: Reaktion Books
- KAY, A. Barry (2006) "100 years of 'Allergy': can von Pirquet's word be rescued?", *Clinical & Experimental Allergy* 36 (5) 555.
- LAQUEUR, Thomas Walter (2003) *Solitary sex: a cultural history of masturbation*. New York: Zone Books.
- LATOUR, Bruno (2000) "On the partial existence of existing and nonexisting objects". In DASTON, Lorraine *Biographies of scientific objects*. Chicago: Chicago University Press.
- LUPTON, Deborah (1996) *Food, the body and the self*. London: Sage.
- LUPTON, Deborah (1999) *Risk*. London: Routledge.
- MCCORMICK, James. (1989) *Reclaiming Paradise. The Global Environment Movement*. Bloomington/Indianapolis: Indiana University Press.
- MILTON, Kay (1993) *Environmentalism. The view from Anthropology*. London: Routledge.
- MITMAN, Gregory (2003) "Natural history and the clinic: the regional ecology of allergy in America", *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 34 (3) 491-510.
- NOVAS, Carlos & ROSE, Nikolas (2005) "Biosocial citizenship". In ONG, Aihwa and COLLIER, Stephen. *Global assemblages: technology, politics, and ethics as anthropological problems*. Oxford: Blackwell.
- PETRYNA, Adriana. (2002) *Life exposed: biological citizens after Chernobyl*. Princeton: Princeton University Press.
- RABINOW, Paul. (1996) *Essays on the anthropology of reason*. Princeton: Princeton University Press.
- RAFFAETA', Roberta (2006) "Allergia e tabu", *AM. Rivista della Società Italiana di Antropologia Medica* 21 383-411.
- SCHAEFER, Torsten (2004) "Epidemiology of complementary alternative medicine for asthma and allergy in Europe and Germany", *Annals of Allergy Asthma and Immunology* 93 (Suppl 1) S5-S10.
- SCHAEFER, Torsten, RIEHLE Alexa, WICHMANN H. Erich and RING, Johannes (2002) "Alternative medicine in allergies: prevalence, patterns of use, and costs" *Allergy* 57 694-700.

- STRACHAN, David P. (1989) "Hay fever, hygiene and household size" *British Medical Journal* 299 1259-1260.
- STRACHAN, David P. (1996) "Socioeconomic factors and the development of allergy", *Toxicology Letters* 86 199-203.
- VON MUTIUS, Erika, FRITZSCH C., WEILAND, Stephan K., RÖLL G. and MAGNUSSEN, Helgo (1992) "Prevalence of asthma and allergic disorders among children in united Germany: a descriptive comparison", *British Medical Journal* 305 1395-1399.
- WAITE, Kathryn (1995) "Blackley and the development of hay fever as a disease of civilization in the nineteenth century", *Medical History* 39 (2) 186-196.
- WARDLAW, A. (1995) "Air pollution and allergic disease: report of a working party of the British Society for Allergy and Clinical Immunology", *Clinical and Experimental Allergy* 23 (3).
- WHO (1986) "The prevention of allergic diseases", *Clinical Allergy* 16 (supplement) 13.
- YEARLEY, Steven (1996) *Sociology, Environmentalism, Globalization. Reinventing the Globe*. London: Sage.

INTRUSIVE AGENTS AND PERMEABLE SELVES. SPIRIT CONSULTATIONS IN DENMARK

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Causes of disease that have to do with the intrusion into the body or personal space of an agent or substance believed to injure the host are common in many societies. Whether the pathogen is related to dirt, germs, allergy or spirits the recipe against such diseases consists in either protection against harmful outside agents through ritual purity, antibodies or other defences, or in driving out or destroying the intrusive agent (JANZEN, 2002: 193). In order to put these measures effectively into operation, however, the intrusive agent must be identified, and in cases where occult forces are suspected to be at work, experts in spiritual matters are often the natural choice. Spirit consultations are well known from classic ethnographic studies of divination, witchcraft and magic in distant times or places (EVANS-PRITCHARD, 1976 [1937]; TURNER, 1967; STOLLER, 1995; WHYTE, 1997). Less is known about such practices in contemporary Western societies, although gradually this picture is changing with the increasing number of “at home” anthropology studies (SKULTANS, 1974; FAVRET-SAADA, 1980; ANDERSON, 2005; MEINTEL, 2007).

These studies show that an unknown number of people in modern societies suffer from disturbing problems such as encounters with spirits or ghosts, misfortunes transferred from random passers-by and transgressions of their personal boundaries by occult intrusive forces. We might think of these experiences as psychotic symptoms to be treated by medical doctors or as emotional problems to be dealt with by psychologists, but these diffuse expressions of ill being and social distress are often marginalised in relation to professional medical systems and referred to other social contexts for their management. Thus, the

participants of this study turned to spirit mediums and clairvoyant counsellors – not as a last desperate choice when facing severe trouble or deep crisis – but as pragmatic ways of handling everyday worries and problems. The aim of this article is to explore the nature of their problems and the ways in which they were dealt with.

In the anthropological understanding of divination and healing, it is often assumed that ritual intervention is a response to crisis and that it leads to a re-establishment of meaning and order, either on a social or an individual level. The risk of this approach, however, is that the intention may be mistaken for its results, and the role of problem solving and creation of meaning is overestimated (WHYTE, 1997: 81). My study of spirit consultations in Denmark supports this critique and shows that instead of providing answers and solutions, the quest to manage uncertainties is just as likely to raise new questions and new problems (STEFFEN, JENKINS & JESSEN, 2005). Attending a spiritualist meeting for example, often leads to questions that are better dealt with in private by a clairvoyant, who may identify problems that require a healer, a hypnotist or an astrologist, and clients may discover along the way that they themselves have spiritual gifts that deserve special attention at clairvoyance schools – one step leading to the other. These observations have led me to question two common assumptions: that divination is a response to crisis and that ritual intervention restores meaning and order.

The study¹ is based on fieldwork conducted among Danish spiritualists, clairvoyants, healers and their clients in 2007 and 2008 when I participated regularly in spiritualist meetings, clairvoyant counselling, lectures and study groups, where spirit mediums explained their activities and passed on messages from “the other side”. I have interviewed clairvoyants and their clients

¹ The study is part of the research project *On the Limits of Reason* carried out in collaboration with Sidsel Busch, Steffen Jöhncke, Kirsten Marie Raahauge and Tine Tjørnhøj-Thomsen. Financial support by the Danish Research Council for Culture and Communication is gratefully acknowledged.

about their experiences, and students have helped me collect data through courses in “the anthropology of magic”.²

The spirit world

The field of spiritual and magical practices in Denmark consists of a number of very diverse cosmologies and activities sometimes referred to as “New Age” or “alternative therapies” that makes it difficult to delimit them using precise criteria. Confronted with this abundance, I chose spiritualism as my point of departure for at least two reasons. First, spiritualism has its origins in Western societies and its history is closely related to modernity and a belief in progress. With its double appeal on the one hand to a broad public audience and on the other hand to researchers organised in societies for psychic research (KRAGH, 2003), spiritualism has significantly influenced cultural ideas about “the spirit world” in Western societies. Secondly, spiritualism as a cosmology is explicitly referred to in a number of New Age therapies and spiritual activities such as clairvoyance, divination, soothsaying, healing and mediumship. My interest lies primarily in examining the activities of spirit consultations as they are practiced in a contemporary Danish setting rather than comparing them to the role of divination in other societies or to the therapeutic mechanisms of symbolic healing in general.

² I want to thank the students who attended the classes in the anthropology of magic autumn 2006 and spring 2009: Mia Agerskov, Lisbeth Albinus, Janne Andersen, Nanette Andersen, Dorte Arnum, Sarah Berggren, Anders Clausen, Pia Fallentin, Jørgen Frichke, Signe Gammeltoft, Birgit Hamming, Birgitte Holst, Karen Iversen, Karina Jensen, Mie Klarsø, Mette Kristensen, Linda Munkbøl, Sofia Pecorelli, Moira Perrier, Anna Rasmussen, Nadia Rasmussen, Mette Skamris, Louise Thomasen, Jacob Thorsen, Ilaria Chierchini, Mia Due, Lise Høj, Sara Iacopini, Lotte Kibsgaard, Maria Kold, Helle Nielsen, Anna Pedersen, Lærke Pålsson, Alice Quine, Anne-Marie Rasmussen, Anne Scherrebeck-Jørgensen, Anne Sidenius, Agnete Suhr, Trine Thygaard-Nielsen, Martina Visentin, Sarah Zak, Pernin Prune, Anissa Tisani, Maria Holten-Andersen, Hannah Dolman and Lars Rømer.

The spiritualist church as a religious institution plays a very limited role in Denmark. Only a few of the mediums and clairvoyants I have met are self-declared spiritualists and very few Danes think of themselves in terms of spiritualism. This may be due partly to the secular character of Danish society in general. Spiritualist ideas, though, are widely shared not only among mediums and clairvoyants but also among people in general. A Gallup poll conducted in March 2008 for the daily newspaper *Berlingske Tidende* showed that one out of three adult Danes believes in the existence of ghosts and the capacity of clairvoyants to communicate with the departed. Other basic ideas of spiritualism such as belief in life after death, the principle of reincarnation and spiritual hierarchies, the existence of spiritual guides and guardian angels and the healing power of spirits make spiritualism an important source of inspiration in various contexts.

The written tradition and the official doctrine of spiritualism are rather insignificant and spiritual practices and beliefs are highly individualised and shaped by the person in question or by local groups of practitioners rather than by remote authorities. Many mediums combine a variety of New Age ideas and personal experiences into their own patchwork of cosmologies. Some 85 persons are organised as members of the Danish clairvoyance association³, founded in 2001 with the purpose of providing information about clairvoyance and securing a high level of ethical standards among clairvoyant counsellors. Many more advertise in local newspapers, on the inter-net and in lifestyle and alternative therapy magazines where they offer personal counselling and healing. Half a dozen schools on clairvoyance operate (BENDIKSEN, 2008), and an unknown number of mediums offer courses and study groups where spiritual skills can be developed.

Originally, the main purpose of spiritualism was to spread the message that there is life after death and that it is possible to gain knowledge of life “on the other side” through communication with the departed. In order to provide evidence for these claims,

³ www.clairvoyantforeningen.dk August 4, 2010.

semi-public experiments were set up for spiritual mediums to demonstrate their skills. The mediums would enter into a trance and materialise spirits in the form of so-called teleplasm: a gauze-like bandage flowing from the mouth, nose or fingers of the medium and forming the shape of a person. Through the intervention of the medium, the spirits would perform and pass on messages from the other side. In societies for psychic research, the mediums were scrutinized by critical scientists exposing them to controlled experiments often resulting in charges of fraud (Kragh, 2003). Today, spiritualism is usually practised in small groups or performed at so-called platform demonstrations such as the ones that took place during my fieldwork in the Daniel Church, situated in the former working class area of Nørrebro in Copenhagen.

The Daniel Church first opened as a spiritualist church in 1932. Fifty years later, it was taken over by the magnetizer Frank Munkø at a time when spiritualism was languishing in Denmark. Munkø, however, managed to revive the church with healing sessions and weekly platform demonstrations, for which he became known throughout the country, not least after his appearance in 2000 on television in the programme “the power of spirits”. Four years later Munkø died, and the church was taken over by his widow and son until the end of 2008 when they had to give it up due to illness and lack of financial and social support. Until then, the church offered weekly demonstrations by spirit mediums for an entrance fee of €10.

Spirit consultations

A Tuesday evening meeting in the Daniel Church usually starts with popular music playing while the participants enter and find their seats. Men make up about a fifth of the group attending the meeting⁴ and people with very different backgrounds and

⁴ That women outnumber men in spiritualist meetings is shown by a number of studies from different parts of the world see Meintel, 2007 for Montreal; Skultans, 2007 for Wales; Anderson, 2005 for Iceland.

of all ages, except children, are represented. The owner of the church welcomes the audience with a short prayer for the protection of those present, introduces the two mediums, who prepare themselves for the performance through meditation or prayer, and then leaves the stage for the first medium to take over. The medium informs the audience about the procedure and explains the importance of their positive attitude and active participation in order to attract the good spirits and make the energy flow. She then begins to pass on messages from the other side. The communication with the departed takes place through the medium and typically falls into three parts: first, the spirit has to be identified by production of evidence, secondly, the relationship between the departed and a living person present in the audience is negotiated, and finally, the messages from the departed will be passed on.

Platform demonstrations present a continuation of the spiritualist tradition of documenting life after death and during a 90 minute evening session, each of the two mediums will typically pass on messages from five to ten spirits. The production of evidence, in the form of correct information about and an accurate description of the departed, is crucial for the medium to obtain credibility among audience members. In practice, the medium enters into a process of negotiation with those present, providing a detailed description of a person and, after a while, asking for a response from the audience, which may either confirm or disconfirm the information given.

The demonstrations serve as a market place for the mediums to present their skills and recruit clients for individual counselling. Through their performance, they seize the opportunity to feed the curiosity of the audience by passing on partial messages and by suggesting that these may need further exploration in a more private context.

A pamphlet from the Danish association of clairvoyants informs the clients that a clairvoyant may help other people through counselling by mediating messages from the individual's spiritual guides. Thus, the clairvoyant acts as a channel for the passage of messages that are not immediately accessible to the client herself. The messages are passed on to the client at a so-called sitting,

and the client can expect to receive information about how to go about changing emotional problems, engaging in personal development and gaining insight into future opportunities.

The client is instructed to sit face-to-face with the clairvoyant and to avoid crossed legs or arms in order to let the energy flow freely between the two. It is possible to ask questions in relation to the messages given, but one cannot demand answers from the spirit world. In this sense, clairvoyant sittings differ from other therapeutic encounters where the client is expected to be much more active and give information about herself. Compared to psychotherapy, the relationship between therapist and client seems to be reversed with the therapist as narrator and the client as (active) listener.

The clients appreciate this difference and the room for interpretation that it allows. The information from the spirit world provides them with an abundance of meaning from which they can pick and choose the parts best related to the content of their experiences. While medicines prescribed by doctors are reserved for symptoms that correspond to problems defined by diagnoses, and psychotherapy requires a specific – and often demanding – presentation of social and emotional problems, the spirit world is much more inclusive, letting in other dimensions of meaning as well as offering other potentials for action.

Sensitive problems

Catherine, a former schoolteacher in her mid-forties and the mother of three children, recounted how her first involvement with spirit counselling began at a platform demonstration that she attended with some girlfriends, out of curiosity and purely for the entertainment. During the performance, however, she became more and more convinced that the medium actually possessed extraordinary skills since she could describe in detail Catherine's late grandmother. The medium unveiled information about the social relationships between members of the family that resonated well with Catherine's own experiences, and she encouraged Catherine to pass on greetings from her departed

grandmother to other family members. The evening ended with a lottery where Catherine happened to win a clairvoyant “sitting” with the medium, the first in a series as it turned out with one step leading to the other.

The issues typically brought up in platform demonstrations as well as in individual sittings demonstrate ongoing preoccupations with personal boundaries and their transgression by outsiders. Many Danish women are employed in welfare work as teachers, nurses, home care assistants and therapists, placing social relations at the core of their activities in both their private and professional lives. They must relate physically and emotionally to the needs of their fellow human beings on a daily basis and are expected to sort out the logistics of social interaction. Those who are in the midst of their lives are often caught between obligations towards young children and ageing parents. Welfare work is poorly paid, family obligations tend to be taken for granted, and thus their services pass rather unnoticed, without the social acknowledgements of money or status.

The messages from the spirit world give voice to the dislikes and burdens carried by these women and resonate well with their everyday experiences and their need to create space for themselves. The burden of social relationships may not be addressed directly but is often translated into more subtle and generalised themes that allow for some freedom of interpretation without compromising moral obligations. A common complaint is formulated as an inability of the women to shield themselves from the emotions of random passers-by or from free-floating spirits. They feel that they involuntarily pick up sensations from their surroundings and that they are hypersensitive to diffuse expressions of pain and misfortune. Catherine explains:

Last summer we went to London on holiday, and we were just walking down the street sightseeing. I have suffered from fits of anxiety before and then suddenly I feel it coming. There is a woman approaching us in the same street. She is dressed in a brown suit, quite ordinary, and the moment she passes me, I feel the anxiety overwhelming me. Oh no, I think, not now and why here? But then I realize that it felt as if it came from that woman, and perhaps I am just absorbing her misfortune. It seems that I function like a sponge for other peoples' pain. That made good sense to me, and I actually managed to overcome it when a bit later we passed her again on

the other side of the street. I have this special empathy in me, so I easily take on the condition of others.

Back home, Catherine worries about her job as a schoolteacher which she finds increasingly stressful and demanding due to the pressure from pupils and their parents to deal with social and emotional problems not strictly part of her duties as a teacher. At the clairvoyant sitting, she asks the spiritual guides whether she should quit her job, and the medium answers promptly: "Yes, you give way too much of yourself and get much too little in return." The message supports Catherine's own evaluation of the situation and later that year she decides to quit her job as a teacher and replace it with one as a sales assistant. It is worth noting, however, that initially it was not a crisis in her job situation that led Catherine to consult a clairvoyant, but rather the clairvoyant consultations that helped her identify the problem and subsequently take the consequent decision to quit.

Intrusive agents

The relationship between medium and client is characterised as one of intersubjectivity and empathy rather than objectivity and professional distance. In contrast to their experiences from other therapeutic encounters, clients often describe how they sense the medium's profound understanding of their problems without their having to explain anything. Acceptance of the content of the client's experience is important because the problem is often of a character that does not easily translate into existing categories. Problems that have to do with separating the emotions of others from oneself, and the struggle to protect personal and physical integrity from intrusive agents are often sensed and presented in diffuse terms. The story of Louise, 49, who lives with her daughter in an apartment in Copenhagen and works as a graphic designer, is a good example. She recounts:

I have experiences with spirits from my very childhood. I grew up in a very ordinary family with a father, a mother and a sister. My parents divorced when I was 10, and I suppose it was such a disruptive experience to me that

I can barely remember anything from my childhood before that. But because I grew up in a family with conflicts, I learned “to read” adults intuitively as a way to orient myself in everyday life. When my parents divorced, my sister and I were separated so she stayed with my mother and I came to live with my father. My father worked a lot and I often came home from school alone. That is when I sometimes saw strangers in our apartment. I wasn’t really scared of them, nor did I tell anybody about them. They looked like fishermen in black garments and they would be talking to each other at the back of the room. Later I began to see things at night that scared me, and my grandma had to move in because I was afraid to be alone, and I still am. I sleep with the light on and have done so for the past 10-12 years. It costs me a lot of energy, I am often tired and I am always on guard.

The sense of being watched, disturbed and drained of energy by spirits has followed Louise in her adult life and has led her to consultations with numerous alternative practitioners, although without much relief. Several clairvoyants have encouraged her to develop her skills as a medium, but Louise has no wish to become a “wounded healer”. She just wants to get rid of the spirits, so she can lead a normal life. When I asked Louise whether she had consulted a doctor or a psychologist for her problems, she responded,

No, I went to a clairvoyant because a doctor would never believe in all this about spirits; I would make a complete fool of myself! And regarding a psychologist – yes, I did consult a psychologist to talk about my anxiety when I was in my 20s. I don’t recall that I got much out of it, even though I told her about the spirits...

During a consultation with a clairvoyant, a suspicion of sexual abuse by her father was raised as a possible reason for Louise’s problems. Rather than solving anything, this suggestion opened up a number of new considerations, problems and actions. Sexual abuse and incest are subjects often addressed in clairvoyant sittings although the extent of these problems is very unclear. In terms of intrusive agents, it may be seen as an expression of the most concrete and extreme form of bodily and personal transgression or violation of personal boundaries. The massive public attention to sexual behaviours that were formerly inconspicuous but more recently have become intolerable crimes makes such acts forceful idioms of intrusiveness, regardless of their actual status

as traumatic experiences, which may explain their frequency in spirit counselling.

The information from the spirit world was, of course, profoundly disturbing for Louise. It dramatically changed her and her daughter's relationship to the father and lead Louise onto a long trail of help seeking among various conventional as well as alternative practitioners, none of them settling the issue or solving her problems. Eventually, she picked up some techniques to get the spirits partly under control by confronting them directly with loud speech, using self-assuring magical spells and material devices – such as spreading salt in the corners of her apartment – to drive them away. These activities were part of her ongoing effort to handle the situation, however, rather than acts that provided her with meaning and order; nor did they solve her problems once and for all.

Permeable selves

Divination and healing are closely related in spirit consultations, and access to the spirit world of hidden knowledge often implies both the ability to identify and to manipulate the hidden forces of energy. Many mediums are former clients who have obtained their skills through their own transformation of problems into healing powers, and they easily empathise with their clients and share their sense of ill being. Although clients such as Louise may not be helped much by their clairvoyant counsellors, they usually feel understood, and describe a sense of resonance and shared experience with the mediums. Their mutual understanding is based on a sense of a permeable self that does not correspond to the normative image of the bounded autonomous person in Western cultures.

While the spiritual mediums have been trained to control the influence of spiritual forces – in fact, one of the most important skills taught at schools of clairvoyance are ritual techniques to “open up” and “close down” your channels – the clients often struggle to get these forces under control (BENDIKSEN, 2007). In an article about extraordinary experiences in anthropology, based

on her own participation in a spiritualist group, Deirdre Meintel describes the special kinds of intersubjectivity that characterise mediumship as “somatic modes of attention”. The feelings and sensations of the group are not strictly individual phenomena because the same things are sometimes seen and felt by others at the same time. Thus, the context offered for intersubjectivity by spiritualism is one in which fields of knowledge and perception not available to everyone are nonetheless shared among the participants as well as between mediums and spirit guides (MEINTEL, 2007: 144, 149).⁵

The intersubjective character of the relationship between participants in spiritualist groups is also noted by Vieda Skultans in her study of spiritualism in Wales. She suggests the term “sociosomatic” in order to grasp the approach to sickness shared in such groups when describing how pain defined as emotion relates to suffering that can be communicated and shared. Pain may be experienced not only by the sick person but also by a healer or any other spiritualists who are “sensitives”. By “taking on conditions”, pains can be shared in much the same way as visual or auditory objects can be shared, in fact, most knowledge of others in the spiritualist community is gained by “taking on a condition”, meaning complete emotional identification with the other. The implication is that any other form of acquiring knowledge of the states of mind of others by more empirical, everyday methods is bound to be incomplete, imperfect and, hence, disappointing (SKULTANS, 2007: 23-24). This may be another reason for the clients’ reluctance to seek help in medicine or psychology.

When the mediums prepare themselves to open up their channels to the spirit world, they engage in prayer and meditation to adjust their level of consciousness to that of the spirits. Susan Greenwood proposes that we understand their magical consciousness as an expanded aspect of awareness that can potentially be experienced by everybody through empathising deeply with another creature in the imagination, so much so that bodily boundaries and distinct notions of self are temporarily

⁵ Thanks to Sylvie Fortin for this reference.

abandoned (GREENWOOD, 2009: 6). This resonates well with the ways in which the mediums and healers of my study account for their experiences.

The identification, or rather fusion, with the spirit world, whether this takes the form of a departed person or the spiritual guides of a client, can be described as a mimetic empathy (WILLERSLEY, 2007: 106). The medium does not necessarily enter into a trance or act as possessed by the spirit, nor does she try to imitate or copy a specific kind of behaviour based on her knowledge of the departed or the spirit guide. Rather, mimetic empathy implies that the medium identifies with the spirit or the client in a way that allows her to take on the other's experience as if it were her own. The boundary between the two does not vanish, and the medium does not altogether lose the sense of her self. Although the boundaries between self and other, and between living and departed, become blurred, the medium maintains a double perspective on the world: that of the spirit and that of her own. This balance between closeness and distance in relationship to the spirit world is reflected in the preoccupation of both mediums and clients with regulating social relationships in their everyday lives.

Regulating proximity and distance

Sharing and empathy are positive values when taking place in a group of trusted insiders, but they make the individual vulnerable and exposed to negative effects outside the group. Sensitive persons therefore strive to regulate their sensitivity towards other people who may appear as “energy-eaters” and exploiters of their empathy. Bente, a woman in her 30s working as a physical therapist, explains:

Some people are energy-eaters – they live by exploiting the energy of others – and I meet some of these in my clinic. Therefore, it may be necessary to protect oneself. You may take a walk in nature to be filled up. Old trees often have ethereal energy that you can profit from. Usually, when I have treated a client, I wash my hands and sit a little while; I brush my body with my hands to clean the aura. In a sense, this is something we all do

automatically to protect ourselves. When we enter a bus, for example, we shut ourselves up against others because we cannot carry all their worries and let ourselves be absorbed by them.

Clairvoyant counsellors suggest various methods and techniques for clients to deal with social relationships and problems of separating selves from others. The methods are characterised by the management of problems through externalisation and an instrumental approach to social and emotional conflicts. Problems are often seen as situated outside the individual and can therefore be the object of direct action through concrete and material devices, recitation of spells, aura cleaning or other kinds of ritual acts. The methods are tangible instruments and magical practices that seem to work, although the relationship between cause and effect cannot be established through recognised rational criteria (Steffen & TjøRNHØJ-THOMSEN, 2004).

The magical techniques demonstrate the pragmatic side of a more coherent theory about the self and its relatedness to the social and natural environment. In this understanding, ideas about the circulation of energies play a central role, whether the circulation takes place inside the individual body, between human beings or between human beings and other physical and spiritual beings. In order to balance the energies, the clairvoyants recommend their clients engage in exercises to defend their personal integrity by, for example, strengthening the aura or soaking up new energy in nature or from the spirit world, as explained by Bente.

Conclusion

In contexts where the boundaries of the person are perceived as weak and where consciousness and sensations are conceived as continuous, “human beings are wizards to each other, and social life is at first magical” Galina Lindquist writes in her book about healing and magic in contemporary Russia (LINDQUIST, 2006: 229). While sharing is considered something very positive in spiritualist groups, the other side of the coin reveals that too much sharing – or uncontrolled sharing – makes the individual vulnerable in

other contexts. Therefore, the problems raised in consultations with spirits are often related to the regulation of proximity and distance in social relations.

The “sensitives” feel that their complaints are marginalised in the public health care system to the extent that their particular way of experiencing problems of intrusion are not taken seriously if presented to a doctor or a psychologist. Hearing voices, seeing spirits or being overshadowed by another person’s sensations are classified as psychotic symptoms in modern Western societies and thus associated with mental illness and the stigma that is attached to it. The informants in this study do not see themselves as mentally ill, and nor do I, but they realise that in order to avoid that label they have to seek help in a setting where their complaints are taken seriously. Understanding can be found among spirit mediums and clairvoyant counsellors who share the same experiences, but have learned to cope with them through magical techniques.

Neither the mediums nor their clients expect the spirit world to solve all their problems or to provide them with answers to deep existential questions. Rather, they make use of the magical techniques available to them at platform demonstrations and individual sittings as a way to reflect upon their situation and meet the challenges of everyday life. They are concerned about the energies and life forces exchanged in social relationships and their particular role vis-à-vis other people in situations where personal boundaries are at stake. Their problems are characterised by intrusiveness and permeability manifested in the exploitation of their sense of empathy and in feelings of being stressed, exhausted and drained of energy. Therefore, they seek ways to strengthen their defences against an intruding life-world and to stand up against the social pressures imposed by their surroundings. This is an ongoing process rather than the result of an acute crisis and their problems are of a kind that may be negotiable over time but not easily solved once and for all.

References

- ANDERSON, Robert (2005) *The ghosts of Iceland*. Belmont: Wadsworth.
- BENDISKEN, Ida Marie B. (2008) *Et åndebul. En antropologisk analyse af clairvoyantes tro, tolkning og tale*. Specialerække 484, Institut for Antropologi, Københavns Universitet.
- EVANS-PRITCHARD, Edward E. (1976) *Witchcraft, oracles, and magic among the Azande*. Oxford: Clarendon Press.
- FAVRET-SAADA, Jeanne (1980) *Deadly words. Witchcraft in the Bocage*. Cambridge: Cambridge University Press.
- GREENWOOD, Susan (2009) *The anthropology of magic*. Oxford: Berg.
- JANZEN, John M. (2002) *The social fabric of health. An introduction to medical anthropology*. Boston: McGraw-Hill.
- KRAGH, Jesper Vaczy. (2003) "Overtro og trolddom. Selskabet for Psykisk Forskning 1905-1930." *Fortid og Nutid* nr. 3.
- LINDQUIST, Galina (2006) *Conjuring hope. Healing and magic in contemporary Russia*. New York: Berghahn.
- MEINTEL, Deirdre (2007) "When the extraordinary hits home: experiencing spiritualism" In GOULET, Jean-Guy and MILLER, Bruce Grandville (eds.) *Extraordinary Anthropology: transformations in the field*. Lincoln: University of Nebraska: 124-157.
- SKULTANS, Vieda. (1974) *Intimacy and Ritual. A Study of Spiritualism, Mediums and Groups*. London: Routledge and Kegan Paul.
- SKULTANS, Vieda (2007) "Empathy and Healing: Aspects of Spiritualist Ritual." In SKULTANS, Vieda: *Empathy and Healing. Essays in Medical and Narrative Anthropology*. Oxford: Berghahn Books.
- STEFFEN, Vibeke and Tjørnhøj-Thomsen, Tine (2004) "Teknologi, selvdisciplinering og magi". *Socialmedicinsk tidsskrift* 6: 520-30.
- STEFFEN, Vibeke, JENKINS, Richard and JESSEN, Hanne (eds.) (2005) *Managing Uncertainty. Ethnographic Studies of Illness, Risk and the Struggle for Control*. Copenhagen: Museum Tusculanum Press.

- STOLLER, Paul (1995) *Embodying Colonial Memories: Spirit Possession, Power and the Hauka in West Africa*. New York: Routledge.
- TURNER, Victor (1967) *The forest of symbols. Aspects of ndembu ritual*. Ithaca: Cornell University Press.
- WHYTE, Susan Reynolds (1997) *Questioning misfortune. The pragmatics of uncertainty in eastern Uganda*. Cambridge: Cambridge University Press.
- WILLERSLEY, Rane (2007) *Soul Hunters. Hunting, animism, and personhood among the Siberian Yukaghirs*. Berkeley: University of California Press.

Acknowledgements

Comments from the participants at the Medical Anthropology at Home (MAAH) conference in France 2010 are gratefully acknowledged.

FIBROMYALGIA, BODILY PRACTICES AND WORK IN RIO DE JANEIRO

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This paper is a partial outcome of the fieldwork and literature review of a research project (2008-2010) developed at the Social Medicine Institute of Rio de Janeiro State University (UERJ), as part of the requirements for the Doctorate course in Public Health.¹ The project adopts a socio-anthropological viewpoint, on the theoretical and methodological levels, and deals with a theme that became an important social and health issue in our culture: the “pain illnesses”, or “bodily pain diseases”. We believe this problem may originate from the current work regime, or *social work regime*.

The study is part of a research line, started in 1998 and finished in 2005, called “New Practices in Collective Health”, whose main objective was to clear up the senses of the new bodily practices disseminated in contemporary culture (LUZ, 2009). The first concern of these studies was the growing search for care on the part of the population, especially women – the ones who most perform “physical exercises” or, according to our research work, *bodily practices* – as a healthy solution for their suffering and pain. This specific project was conducted through the observation of women in a Multidisciplinary Unit Care Program at UERJ’s Sports and Physical Education Institute, which deals with people suffering from fibromyalgia. This Program started in 2000 and welcomes about 50 people each semester.

¹ Sixty women were enrolled in this research project in 2009, but only 35 participate actively. We interviewed these 35 women, and over 80 women with fibromyalgia who did not participate in our bodily practices.

According to the medical definition, fibromyalgia is a syndrome characterized by intense and continuous pain in several parts (“tender points”) of the body. We aim to demonstrate that this illness is frequently associated with work activities, mainly non-domestic work, although a minority of this population only performs domestic activities. Almost all members of our study group, 50 people, are women, and as in the global population, they have both professional *and* domestic work activities. A few members of the group perform domestic activities only.

Our main interpretative hypothesis is that these women express in their bodies the “malaise” experienced in the world of work, where they must face the new productive global regime that demands more and varied activities in the same time span as three decades ago, without any material or symbolic compensation – just the opposite. Also, workers are “being charged” for the success of the intense rhythm of work and increasing number of tasks, and the fact that professionals are supposed to consider the whole process as a *natural part* of the competition among them, point, in our opinion, to a new ideal of a productive worker. This new regime means working under constant stress, which leads to suffering, vulnerability and frailty, to illness, disease, and finally to death.

Fibromyalgia: the biomedical problem

Fibromyalgia has been classified by biomedicine as a rheumatic syndrome, with continuous chronic and diffuse muscular skeleton (and other) pain in the body, which becomes sensitive to touching. It affects 2% of the world population, and accounts for 20% of the population visits to rheumatologists. It is frequently associated with general fatigue, sleeping inaptitude, headaches, morning rigidity, dyspnea, memorizing and concentration difficulty, anxiety and humor alteration, which can degenerate until depression. Bodily pains are common in the neck, back, shoulders, pelvic waist and hands, although any part of the body can be affected (AUQUIER, 2008; CATHEBRAS *et alii*, 1998; EINSIGER, 2003; HAUSER *et alii*, 2009; KOLLNER *et alii*, 2009).

The description of the first symptoms appeared in the middle of the 19th century. Nevertheless, only in 1977 the rheumatologist Hugh Smythe and the psychologist Harvey Moldovsky described the profile of the syndrome and proposed diagnosis and objectives. The average age of the patients ranges from 30 to 60 years, and the illness is common among women. Prevalence of fibromyalgia in the USA ranges from 3.4% among women to 0.5% in men. In Brazil, the prevalence is of 2%, and 90% of patients are women.

Laboratory tests, X-rays, biopsy and muscular tissues did not succeed in displaying any pathological indication. Millions of dollars have been spent in research to investigate fibromyalgia. However, only in the 1990s the word “fibromyalgia” formally entered the medical dictionary, describing a condition characterized by persistent muscular pain throughout the body, frequently followed by severe fatigue, sleeping inaptitude, diarrhea and abdomen swelling, bladder irritability and headache (GROOPMAN, 2000).

Considering the increasing number of people affected, and its debilitating, if not disabling conditions, fibromyalgia became a health subject of international interest. It often appears in the media (newspaper and television), and has become an important theme of medical and psychological meetings, being also addressed by hundreds of internet sites.

As part of our initial research, we conducted a survey on internet sites (May 11th, 2008), where we found some interesting data. Using the Portuguese word “fibromialgia” in the Google (www.google.com.br) we found 823,000 links. Using the word “fibromyalgia” (English) we found more than 7,720,000 links. And with the word “fibromyalgie” (French) there were about 1,270,000 links. Only in the Orkut (www.orkut.com.br) there were 67 communities of people with this illness.

We became surprised with the names of some of the communities: “I have fibromyalgia”, “To have fibromyalgia you must have fiber”, “Fibromyalgia: the soul pain”, “I hate fibromyalgia”, “Fibromyalgia: a pain that never stops”, “Fibromyalgia: the nightmare hour”, “Fibromyalgia: the invisible monster”. Our theme appears then as a provocative social phenomenon, where virtual communities formed by ill people build collective identities and

identifications around their pathology, searching to help each other through testimony, advice and orientation.

To El-Hage *et alii* (2006), the chronic “unexplained” pain can be a somatic manifestation of a psychic suffering, frequently disregarded. It should be necessary, during clinical examination, to take into account the psychic dimension of the illness, and search any previous traumatic background, to exclude the chronic suffering and the onset of co-morbidity. The fact that many patients do not show physiological objective alterations reinforces the belief that fibromyalgia is a psychic pathology. Patients are often considered psychiatric patients, mainly due to the fact that biomedical specialties do not achieve consensual diagnosis. Biomedicine rationally recognizes the legitimacy of pathologies through “objective” biomedical examination, increasingly by image technology. When clinical tests are unable to “see” the disease, the clinical profile remains uncertain and the patient is sent to psychiatrists (TESSER, 2007).

Due to biomedical standardization and to international illnesses classification, fibromyalgia cannot be detailed in its etiology and physical pathological mechanisms, being limited to a multiform subjective malaise. Since it is characterized by invisible features, fibromyalgia continues to be unexplainable, defined by bodily pain associated with depression (SORDET-GUEPET, 2004).

Depression effectively produces negative consequences to the quality of life of patients. As it increases their sensation of pain and incompetence, it makes compliance with the treatment more difficult and decreases the quality of their social relations and life. Patients tend to become isolated and to feel frustrated and defeated (EL-HAGE, 2006; WATSON, 2009).

Depression characteristics such as fatigue, guilt feeling, lack of self-esteem and victimization exacerbate the symptoms, damaging the patients’ strategies to fight the disease. So far, no laboratory diagnostic proof, etiological or physiological explaining causes of fibromyalgia have been found. The lack of tests, the so-called “self-explaining” medical information, or even the missing information on the organic causes of fibromyalgia is an important problem to be solved by biomedicine diagnosis and therapeutics for fibromyalgia:

I would add that my life revolves around the pain, because I never know how I will be going to the movies, working, visiting my family, my friends; I feel pain 24 hours a day since I was 47 years and I believe that this pain is driving me to depression. What is making me sad is that I want to cry. I try to raise my head and move on, but the pain and fatigue are a plague undermining the little things we do everyday, and it is becoming impossible to perform the simplest tasks of everyday life (49 years, single, bank employee).

Tesser (2007) argues that the biomedical paradigm is based on overestimating biomedical scientific research as “The Truth”. Only standardized tests or statistics biomedical protocols can state whether a fact is knowledge, whether it is valuable or not. These tools are considered as *truth producers*.

Truth concerning the cure of human beings became the cure of the diseases defined by an international code. This kind of procedure demands methodological scientific legitimization, and statistics data for corroboration. Clinically controlled trials (medicine x placebo, medicine x medicine) became the accepted *truth producers*. Validation and truth establishing cure moved from the patient’s daily treatment, from the doctor’s empirical experience, to the field of scientific experiences studies, which value interference, controlled trials and cohort studies. Pride concerning therapeutic knowledge became being informed of the last results of meta-analysis and large international case-control studies on fibromyalgia.

The social construction of diagnostic truths and therapeutic procedures generally monopolized by controlled clinical experiences and by pharmacy and chemistry industries often becomes a process of social deresponsibilization of the therapeutic mission of physicians. How can we establish fibromyalgia diagnostics, care, and cure in the contemporary complex social and medical context?

I did several tests, a diagnosis of exclusion assessed me as having fibromyalgia. Until I found this medication I was a year and a half going to all orthopedic you can imagine, I did all the exams and the answer was always the same, I had nothing – nothing? I was in pain, much pain, 24 hours a day. Fibromyalgia does not show up in laboratory tests and most doctors do not listen to their patients and not the survey, just look at tests and read reports. In the beginning was very difficult, I thought I was crazy (32 years, married, teacher).

The pain is intense, back, arms, wrists and legs. I began searching for various medical specialties: general, orthopedic, and others. I thought I was with a serious disease, even cancer. The doctors laughed at me when I asked if it was cancer. Nobody could figure out what I had. I did several tests that did not show anything (31 years, single, teacher).

Luz (2004, 2005), with her studies on public health care system users in Brazil, points that biomedicine is not being able to support the increasing demand for therapy created by patients. Therapeutic procedures focus on the struggle against established illnesses, or their control, apart from people and their lives, becoming a process of rationalizing medical interventions on the diseased bodies. Considering the lack of practical and theoretical formation among health care professionals, social sciences have been summoned, in the last three decades, to cooperate with the health area, mainly in Collective Health field, our field of work.

Social and cultural nature of pain

The fact that pain is a universal individual biological answer to harmful stimuli originated inside or outside the human body does not prevent us from considering it suffering and the behavior they may provoke in people – whether verbal or non verbal – may aim at suppressing it, but they are always related to culture. Social groups and society have the function of attributing to pain the status of normality, or fatality, or even to evaluate it as punishment, legitimating it, as in the case of some social rituals of self-torture that aim at the conquest of social prestige (FERREIRA, 2004).

Pain is generally understood as a sensorial and emotional unpleasant experience, associated with potential or current lesion. But is pain organic or psychogenic? To biomedicine, pain is a consequence of a body lesion that must be found. When we are not able to find the physiopathologic mechanisms of pain, its etiologic roots must be explained by means of its psychological or social components. However, nowadays another answer is being given to this question. Pain is at the same time a biologic, a psychic and a social experience. Therefore, it is a biopsychosocial form of existence.

Sarti (2001) asserts that pain goes far beyond biomedical limits, since it is a manifestation of the relationship between the individual and society. The ways of feeling and expressing pain are ruled by cultural codes, and pain itself is built with meanings attributed to and shared by the collectivity, which establishes the forms of manifestation of feelings. It is inserted in a universe of symbolic references, being itself a cultural fact. Mauss' masterpiece (2005 [1921]) underlines that our feelings, verbal expression, weep and grieving are not only psychological or physiological, but also social phenomena. Also for Le Breton (1995), pain is not only a "physiological fact", but mainly an "existence fact". It is not a body that suffers, but a human being who belongs to a culture and a society, with a singular subjectivity and history. The close relationship with pain depends on the very meaning it will have at the particular moment it touches the individual.

Pain complaint, the main demand for care at UERJ's Multidisciplinary Treatment Program for Patients with Fibromyalgia, where we conduct this case study, and the recurrent search of patients for "sick leaves", in order to be allowed to spend a long time away from work, must not be reduced to the symptoms of fibromyalgia, but must be considered as a biopsychosocial phenomenon, a social result of collective relations, of cultural signs and meanings.

Work and pain in modern societies

The classical Political Economy considered work the source of richness of nations and the foundation of the right to private property. With the advent of the Protestant Reform, in the 17th century and later, a life devoted to work, to production of richness and welfare became a privileged way of living demonstration of one's faith. The ascetic way of work is linked to the modern capitalistic *ethos*, through the values that men recognize as constitutive of themselves as social, creative and reflexive human beings, differently from animal activities, seen as purely instinctive. In this sense, Castel (1995) shows us that work has been the main historical support of human inscription in the social structure.

Dejours (1992) tells us that the studies on work use data concerning violence in the factories, offices and industries, or in the production lines, among several others, to reveal the suffering of the workers. To this author, such data are important, but insufficient because they do not consider the psychopathology of work, i.e., the psychic suffering of the subjects brought by work itself.

Our interpretative hypothesis, arisen from the field activities conducted so far (ethnography, participant observation, interviews with participants of the Program) is that the work regime itself – with its accelerated rhythm, twisting daily life, urging for productivity, employment instability, and the compelling competition to keep one's job – is the major conditioning factor of getting ill among working women. We also consider that the malaise arising from this situation and the impossibility to respond to these demands may be, and are being manifested in the form of bodily pain, thus explaining the increasing number of fibromyalgia diagnoses.

Work regime and fibromyalgia: women with pain

When we started interviewing women with fibromyalgia, we were interested in knowing whether these women needed to obtain, at any time, a sick leave to stop working due to their pain; if pain was present in this case; and also to obtain information about their social regime of work. Among several interviews, we selected the following:

I used to work in an accountability Office. It was a time of too much demand and no help. At least I was doing the work of some other people. I think that it indeed contributed to my illness, of course. I had to take a sick leaf for three years. This was the worst period of my life (29 years, single, financial analyst).

I was missing [work] because of it (pain), for my crises came always close to my guard nights. Presently I am in a period of six months of license. When I'm not working my crisis decreases in 90%. I think that it's my work that contributed to my disease. It was physic, psychic and emotional stressing. The very nature of the work makes us ill. Fibromyalgia process was definitely

developed there. We are more tense in work, and this cause you more pain (27 years old, single, penitentiary agent).

Working 28 years in a bank, where I suffered a lot of pressure over the years, either heads, whether customers. Over the years, I received much moral harassment, pressure to meet targets, increased workload. All this resulted in repetitive strain injuries and pain in the body. As this is a psychosomatic illness, everything is getting worse. I was typing the whole time. Increasingly in pushing for faster, faster to meet, attend out of hours, bullying, name calling. So I say that the work contributed greatly to my illness. I have many classmates bank affected by fibromyalgia, DORT, depression (49 years, divorced, bank employee).

We can notice in the quotations above that the subjects report their work overload and the work environment as intimately related factors. Sometimes we notice that these women consider work “atmosphere” as the rupture point for the illness onset.

Several factors are co-related to understand the muscular skeleton disturbances. Organizational factors related to social regime of work, like restricted time to achieve activities, or lack of time for recovering forces, are part of main risk factors, as well as social psychological ones (constant stress, lack of support from senior ranks, and collective frailty).

The weight of social and psychological factors related to work (mainly professional stress) in the manifestation of muscular skeleton disturbances is real indeed (DURAND, 1978; ROQUELAURE, 2008). When colleagues do not believe in your pain, when bosses prioritize productivity, instead of the worker's health, the working woman tends to keep the “high rhythm”, since she has not “proved” her pathology. She is not able to prove neither her suffering nor her illness.

According to Desriau (2008b), skeleton muscles disturbances are the most recognized professional diseases. If these pathologies are not potentially mortal, as cancer, they are the source of severe disabilities, which means a threat to health, employment and social life of the affected people.

A valuable finding in our study is the relationship between the social order of work and teaching. There is a particularity in this professional activity that deserves our attention. An impressive number of women with fibromyalgia are teachers, and

report their professional everyday lives, marked by symbolic pain (humiliation, low salaries, verbal or physical aggressions, etc.), which turns to pain:

I do believe that what has caused my fibromyalgia was the work, because it was very stressing and as a consequence I began to have insomnia and lack of physical activity. I believe that I became ill because of my work (24, single, school teacher).

I had to quit a permanent function in the State Educational System in consequence of my illness. In several periods of the year I need to take sick leaves due to fibromyalgia. I also had to deal with work colleagues who believed that I am a bad professional in function of my absences, or the bad condition in what I go to work when I am in crisis (35 years, married, teacher).

What triggered my illness were nervous crises because of work. I taught all shifts with classes of 60 students. It was terribly stressful because of the number of students in the room. In the work I could not fail ever. It was even slave labor. My work contributed to the illness. It contributed a lot and I regret having chosen this profession (44 years, single, school teacher).

In all reports so far, we have found the work environment, the tension in work and its unstable and degrading regime closely related to suffering and getting ill. All the subjects reported how their work activities contribute, under certain conditions, to their illness process.

The productive changes that took place in Brazil, as in others societies, in the last decades, are closely related to certain illnesses in the teaching work.

The rapid economic changes brought about new demands in the educational system, expressed in new forms of management and organization of school work. These changes, which imply tasks and activities that did not exist before – and that are not included in the salary – have created, as a consequence of the intensification of the teaching work, a general malaise in this professional category. The teaching activity increases if not generates intense and generalized bodily pain in teachers, mainly among women, who are the great majority of this category of workers.

Final remarks

So far there have been several answers to our questions about women with fibromyalgia, approaching their suffering and getting ill at work. It seems that the loss of senses and meaning in work is the major determinant of this illness. Since work is a vital element for developing creative activities among human beings, or for having social approval and collective support, this loss may be one possible interpretation, if not an explanation for the present situation.

The social order of work in the capitalistic world production is a key factor to be assessed as a possible explanation for the process of getting ill in several categories of workers who are losing professional identity due to the degradation of their work (LUZ, 2006, 2007, 2008).

In our case study, we try to explain the activity of work as being a major generator of suffering, instead of bringing personal and collective self-esteem, creativity and accomplishment. Are there any strategies to go beyond this situation? We could see in this study and in previous ones that the collective bodily practices, holding positive collective values as solidarity and mutual support, are health alternatives that create social strategies and sociability that help reduce the feeling of oppression and suffering in work, source of pain and illness.

In a survey conducted in 2008 as part of our field work, we found some interesting data: 50% of women participating of the Project reported high or very high stress in work. About 22% were on sick leave because of bodily pains. Other studies found that 58% of women that became ill in 2003 had intense skeleton muscular pain (QUÉRUEL, 2008).

To approach and explain the new order of work remains a major problem to social sciences, which imposed sudden changes in the rhythm and intensification of labor activities, without providing material or symbolical gratification. The productive worker must now be available at any moment to meet the demands of his organization, minimizing his own and familiar interests. As a consequence, the loss of professional identity increases. Work is no longer a way of creating and expressing meanings for life. We

could attest the existence of a “malaise” related to tension in work, to the lack of recognition and reward concerning the importance of what is being done, and the mental and physical efforts of workers being disregarded, generating continuous suffering and illness.

References

- AUQUIER, Louis *et alii* (2008) “La fibromyalgie” *La Revue de la Médecine Interne* 29 (2) 161-168.
- CASTEL, Robert (1995) *Les Métamorphoses de la question sociale*. Paris: Librairie Arthème Fayard.
- CATHEBRAS, Pascal, LAUWERS, Anne & ROUSSET, Hugues (1998) “La Fibromyalgie: une revue critique”. *Annales de Médecine Interne* Paris 149 (7) 406-414.
- DEJOURS, Christophe (1992) *A loucura do trabalho: estudo de psicopatologia do trabalho*. Tradução de Ana Isabel Paraguay e Lúcia Leal Ferreira. 5 ed ampliada. São Paulo: Cortez.
- DESRIEAUX, François (2008) “Troubles musculo-squelettiques: à quand une prévention durable?” *Santé & Travail* 62 (avril) 25.
- DURAND, Claude (1978) *Le travail enchaîné. Organisation du travail et domination sociale*. Paris: Éditions du Seuil.
- EISINGER, Jean (2003) “Évaluation clinique de la fibromyalgie” *La Revue de la Médecine Interne* 24 (4) 237-242.
- EL-HAGE, Wissam, LAMY, Celine, GOUPILLE, Philippe, GAILLARD P., CAMUS Vincent (2006) “Fibromyalgie: une maladie du traumatisme psychique?” *La Presse Médicale, Paris* 35 (11) 1683-1689.
- FERREIRA, Jaqueline (2004) *Soigner les mal-soignés. Ethnologie d'un centre de soins gratuits de médecins du monde*. Paris: L'Harmattan.
- GROOPMAN, Jérôme (2000) “Hurting All Over: With so many people in so much pain, how could fibromyalgia not be a disease?” *The New Yorker*, 13 nov.
- HAUSER, Winfried, EICH, Wolfgang, HERRMANN, Markus, NUTZINGER, Detlev, SCHILTENWOLF, Marcus, HENNINGSSEN, Peter (2009) “Fibromyalgia syndrome: classification, diagnosis, and treatment” *Deutsches Aerzteblatt International* 106 (23) 383-391.

- KOLLNER Volker, BERNARDY, Kathrin, HÄUSER, Winfried (2009) Diagnosis and therapy of fibromyalgia syndrome. *Dtsch Med Wochenschr* 134 (22) 1163-1174.
- LE BRETON, David (1995) *Anthropologie de La Douleur*. Paris: Métailié.
- LUZ, Madel Therezinha (2005) "Cultura Contemporânea e Medicinas Alternativas: Novos Paradigmas em Saúde no Fim do Século XX" *PHYSIS: Revista de Saúde Coletiva*, Rio de Janeiro, 15 (Suplemento)145-176.
- LUZ, Madel Therezinha (2004). *Natural, racional, Social: razão médica e racionalidade científica moderna*. 2 ed. ver. São Paulo: Hucitec.
- LUZ, Madel Therezinha (2009) "New Practices in collective health care" AM, 17-18/ October 2004, Perugia, ARGO, 109-122.
- LUZ, Madel Therezinha (2006) "Fragilidade social e Busca de Cuidado na Sociedade Civil de Hoje". In: PINHERO, Roseni & MATTOS, Rubens A. (Orgs). *Cuidado: as Fronteiras da Integralidade*. 3 ed. Rio de Janeiro: CEPESC/UERJ/ABRASCO.
- LUZ, Madel Therezinha (2007) "Perda da ética no trabalho acadêmico: geração de sofrimento e doença entre trabalhadores universitários a partir do produtivismo como valor-fim entre pesquisadores docentes". In: PINHERO, Roseni & MATTOS, Rubens A. (Orgs). *Razões Públicas para a integralidade em saúde: O Cuidado como Valor*. Rio de Janeiro: IMS/UERJ/CEPESC/ABRASCO.
- LUZ, Madel Therezinha (2008) "Notas sobre a política de produtividade em pesquisa no Brasil: Consequências para a vida acadêmica, a ética no trabalho e a saúde dos trabalhadores" *Política & Sociedade: Revista de Sociologia Política*, Florianópolis 7 (13) 205-228..
- MAUSS, Marcel (2005) "A Expressão Obrigatória dos Sentimentos (Rituais Oraís Funerários Australianos)". In Mauss, Marcel *Ensaio de Sociologia*. Tradução de MAUSS, M. (1921). L'expression obligatoire des sentiments (rituels oraux funéraires australiens). *Journal de Psychologie* 18 425-434.
- QUÉRUEL, Nathalie (2008) Quand le travail malmène les femmes. *Santé & Travail* 63 6-7.

- ROQUELAURE, Yves (2008) "Des pathologies parfois très invalidantes" *Santé & Travail* 62 (Troubles musculo-squelettiques: à quand une prévention durable?) 36-37.
- SARTI, Cyntia A. (2001) "A dor, o indivíduo e a cultura". *Saúde e Sociedade*, São Paulo, 10 (1) 3-13.
- SORDET-GUEPET, Hélène (2004) "L'insaisissable fibromyalgie". *L'Évolution Psychiatrique* 69 (4) 671-689.
- TESSER, Charles Dalcanale (2007) "A verdade na biomedicina, reações adversas e efeitos colaterais: uma reflexão introdutória". *PHYSIS: Revista de Saúde Coletiva*, Rio de Janeiro, 17 (3) 465-484.
- WATSON, Nathaniel *et alii* (2009) "Neurologic signs and symptoms in fibromyalgia". *Arthritis Rheumatism*, 60 (9) 2839-2844.

LIVING A CHRONIC ILLNESS: A CONDITION BETWEEN CARE AND STRATEGIES

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In 2004, in Italy, approximately 42,000 people were undergoing dialysis. The treatments were conducted in 850 facilities all over the country, with significant variations from region to region.

The Complex Nephrology and Dialysis Unit (UOC), in the Santo Spirito in Saxia Hospital in Rome, was established in 1992, but its achievement was long and complex. Only in 1997, the new centre was completely opened, offering: haemodialysis, peritoneal dialysis service, outpatient nephrology service, inpatient consultation service and day hospital service. There were six doctors involved in the overall activities of the Unit, and two of them were in charge of the haemodialysis treatment.

This paper will analyse some of the results of an investigation I carried out in 2005 and 2006 in the centre for haemodialysis treatment at the Santo Spirito Hospital.

The term haemodialysis refers to a therapy that is adopted when kidneys are in renal failure. The possibility for patients to survive is strictly bound to the machine that carries out vital renal functions, and thus to the hospital, where actually haemodialysis takes place.

Medical technology, in many cases, has increased life expectancy, the possibility to defeat diseases, as well as diagnosing, rehabilitating, and relieving suffering. However, there are conditions in which medical practice can exclusively guarantee life preservation, and the restoration of a temporary normality. I refer to the cases in which the medical technology cannot heal, but just allows the permanence in the disease condition, thus determining the dependence of the ill person from biomedicine and from the

medical technology itself¹. In this way, therapeutic practices such as haemodialysis contribute to the creation of communities of patients, doctors and nurses that share spaces where the therapy takes place and build relations that go beyond the interaction between health professionals and patients to become personal relationships². These communities are characterised by specialists, narrations and traditions, which Rabinow (1996) has defined as biosociality.

In this article I will attempt to analyse how patients in haemodialysis deal with their condition of chronic illness and dependence on medical technology. I will also focus on the construction of the 'good patient'. With this term I mean a person or, better, a body that experiences health as a project and not as a status, during the therapy and even at the stage of pre-dialysis. The construction of the "good patient" seems to be made by means of prevention, education, control, monitoring.

The person affected by a renal failure is surrounded by the coordinated effort of facilities, health centres, transplant centres, and health professionals that attempt to provide a sustainable treatment. General practitioners and nephrologists that follow the patient in the pre-dialysis stage, trying to delay the dialysis treatment, and thus the renal failure; dieticians; psychologists that support the patient in dealing with a chronic illness, and, at last, social workers: these figures constitute a specialised group that creates the discourse through which the person is progressively transformed in a dialysis patient, even before the actual beginning of the treatment.

Once the patient is aware about his/her condition and the factors that can increase the risk of mortality or worsen his/her state, the doctors delegate to him/her the responsibility for his/her health and life. Responsibility to be intended in its 'common sense' meaning, that is to say as a rational ability of self-control, for example about the management of the diet and of the liquid,

¹ See, for example, LOCK, YOUNG and CAMBROSIO, 2000 and LOCK and GORDON, 1988. For a discussion on this topic in my research see EUGENI, 2009.

² See, for example, ALEXANDER, 1981.

but also about the monitoring of the body. The patient feels in charge of his/her health, but powerless due to the impossibility of controlling all the aspects involved in preserving it.

In the following pages, particular attention will be given to those strategies that the patient carries out in order to avoid delegating his/her body and life to the therapy, and to think of him/herself beyond his/her condition of illness. When life depends on a machine, it becomes necessary for the patients to rethink their new life, which has been defined by them as survival, as product of the technical progress.

The research

The research has been carried out through participant observation of the practices and activities that took place within the dialysis ward in the Santo Spirito in Saxia Hospital. Eighteen individual interviews and three focus group discussions (FGDs) with patients, doctors and nurses were also conducted. During the research I preferred to adopt semi-structured interviews in order to let the informants feel free to talk about suffering, treatment and work experiences. I have had long and informal discussions with patients, doctors and nurses, before, during and after the haemodialysis treatment. I have also participated in discussions as an observer, also contributing to them, inviting patients to reflect on events or previous debates. The FGDs were organised in the ward, during the treatments. Two of them involved only physicians and nurses; the subjects of the debates were: the choice of working in a particular area such as haemodialysis and the difficulties of working with patients who cannot be healed. The third one involved four patients and was about how to deal with some aspects related to their health condition and to the care, with a particular focus on transplant and diet.

When the present research was carried out, there were 32 patients, distributed in four shifts, two for the morning and two for the afternoon. Only fifteen of them – eleven males and four females – agreed to be interviewed. They were between 40 and 90 years old, however – aside from two relatively young subjects – the

average age of the informants was 65 years-old. As a consequence of the haemodialysis treatment, some of these patients left or changed their job. They lived near the hospital and belonged to the middle-class. As a matter of fact, this area is populated by a huge rate of elderly population. Compared to the rest of the elderly population of Rome, this has special features such as: a high level education and a high percentage of former clerks, teachers and professionals, related to the main activities developed in the area: services, trade, legal and accounting advice.

During the period in which this research was carried out, the haemodialysis treatment was taking place in a small room with eight beds, organized in pairs. The haemodialysis machine was next to each bed. During the treatment the patients were motionless on their beds and were attached to the haemodialysis machine (artificial kidney) generally by a fistula: a modification of the arm through which the blood first is taken and then, after the purification, is reintroduced inside the body. The patients were lying on the beds and, in this position, they could not check the information that appeared on the screen of the machine, unless they explicitly asked to turn it towards them.

During each treatment, two or three nurses, one doctor and, often, one attendant were in the room.

Chronic illness: who is the person in haemodialysis

The ill person undertaking haemodialysis treatment is defined as chronic. This condition leads to a tight bond with biomedicine, which often cannot be broken. Doctors and nurses refer to people in haemodialysis as patients, although they cannot be identified straightforwardly as ill persons. Very often the people I interviewed talked about themselves as individuals in an ambiguous condition, not perceiving themselves neither as healthy nor as sick.

The category of "chronicity" was introduced in biomedical language in opposition to one of "acuteness" at the beginning of the xx century. In a certain way it is a challenge to biomedicine, because sometimes it is really difficult to determinate precisely

when a disorder became chronic³. As Honkasalo (2001), as well as Estroff (1993), have underlined, the concept of chronicity is strictly connected to the impossibility of the cure, and for this reason it challenges the power of biomedicine, differently from the acute states which, in many cases, can be cured thus remaining under its control.

Sometimes the chronicity is made possible by the medical technology itself, and cures and treatments connected to this can cause more troubles and new suffering. This condition is connected to a deep inscription of the biomedicine in the body of the patient and impose to him/her a continuous relation with health professionals who diagnose and treat⁴ him/her. The contact with doctors and nurses, the intrusiveness of the treatments and often the visibility of the disability, sometimes seem to cause a lowering of the privacy⁵, not only in the therapeutic context but also in other spaces and interactions.

The chronic states have often an uncertain beginning, which makes it difficult for the person to identify precisely when the disease has started. As chronic, the ill person is part of that new community which Frank (1995) has defined as "remission society": he/she lives the disease not as a transitory state but as a permanent one. The chronic state is constant in time, often lasting the patient's whole life⁶, causing a deep redefinition in the management of time and in self-perception⁷, a "biographical disruption"⁸ which modifies the personal routines and the lifestyle of the ill person and of the people around him/her. The ill person changes his/her self-perception from a person who has an illness to someone who is an illness: the diagnosis results in absorbing and shaping the identity of the person becoming inseparable

³ HONKASALO, 2001; BURY, 2005.

⁴ ESTROFF, 1993.

⁵ ESTROFF, 1993.

⁶ BACHIMONT, 1998.

⁷ CHARMAZ, 1983, 1991.

⁸ BURY, 1982; See also VAN DONGEN and REIS, 2002.

from the self⁹ and eclipsing other attributes, roles and features of the ill person.

The chronic states share a floating course characterised by an alternation of improving and worsening phases, then by a constant uncertainty¹⁰; the need of daily cures adapted to the course of illness; an unpredictable results¹¹.

The difficulty and the restructuring determined by those states in the life of the ill lead often to the making of strategies for mobilizing social and material resources¹². The chronic states, indeed, need material and interpersonal help, which cannot rely only on the individual and his/her family, but require also the support of a larger community and of the health and social services.

People undergoing haemodialysis experience illness as a permanent state, since they cannot be considered as recovered¹³. Kidney failure, as a chronic disease, is not a break between two healthy conditions. For the people affected by it, the reintegration process within the community of the healthy is temporary, and often invalidated by physical exhaustion caused by the therapy and by the emotional distress of having to return to the hospital. As a disease, kidney failure cannot be relegated to the past, and it influences the future.

In the imaginary of people in haemodialysis, terms like "patient" and "ill" do not have the same meaning: the former indicates a customer within a health care system that provide services, while the latter refers to a more intimate condition that the person can evaluate on the basis of a broader perception of his/her life. The intrusiveness of the haemodialysis in everyday life allows the person to determinate the condition of health or illness depending on a variety of factors that are related not only to their organic condition, but also to the specific evaluation of quality

⁹ ESTROFF, 1993.

¹⁰ COMAROFF and MAGUIRE, 1981.

¹¹ BURY, 2005.

¹² BURY, 2005.

¹³ RUSS, SHIM and KAUFMAN, 2005.

of life. This is because the therapy leads to the restructuring of family and working ties, as well as friendships. Life is organized around the treatment, which modifies the 'natural' self-perception and personal habits, forcing the sick person to a new time management¹⁴.

During a conversation in the haemodialysis ward, a doctor highlighted how in his view these people are actually patients only while they are in the hospital. However, the condition in which they live appears to be different: they experience the impossibility of subtracting themselves from the role of patients, since, even in private spaces, the techniques to maintain their body as an optimized body for the long-lasting haemodialysis treatment make them constantly subjected to a therapeutic project. One can say that they learn to live life constantly as a "therapeutic project".

Rebecca, a 70 year old patient, identified haemodialysis with dependence. With this term she meant a dependence that one could define as 'direct', since, during the treatment, the patient is motionless on the bed: movements could create problems for the artificial kidney and thus forcing the nurse to intervene. During the treatment, patients depend on nurses, but also on the artificial kidney, which makes the person's life possible. This dependence forces the patient to live close to the haemodialysis facility, also because of the difficulty to find a bed available in other hospitals. Nevertheless, in Rebecca's story, dependence refers also to the "indirect" bond that links the person and the therapy through the practices that would optimize the haemodialysis treatment and make it more tolerable. Also, in the domestic sphere, medical prescription imposes rules on the managing of the body, starting from the diet to the sleeping position, whereby the person, in order to help the drainage, has to keep elevated the arm where the arteriovenous fistula is "built". With this effort, the patient is constantly attempting to integrate this dimension of suspension within the 'normal' flow of his/her existence, and vice versa to integrate his/her normality, his/her time, within the space of the hospital.

¹⁴ BURY, 2005; CHARMAZ 1991. For a discussion on this topic in my research, see EUGENI, 2008.

Constructing the patient

The discourse of the health professionals responsible for the haemodialysis treatment constructs patients through a double rhetoric: that of the ‘good patient’¹⁵ and that of the ‘child’. These two representations correspond to the discourse of doctors and nurses respectively. They both form from patient’s crucial co-operation towards the improvement of his/her quality of life, which leads to a progressive colonisation of the social contest by biomedicine. Haemodialysis is presented as a necessary yet invasive treatment, with which it seems indispensable for the patient to compromise, to co-exist. This treatment can keep the person alive, but it needs a strong co-operation of doctor and patient, which the latter is forced to perform. Medical authority imposes on her/him what he/she has to do, and what he/she has not to do, how he/she has to behave, and at the same time, indicates what biomedicine can do if he/she follows its rules.

The relationship between patient and health professionals develops as a contract, as Taussig (1980) puts it, which implies a reciprocal commitment among the parts that subscribe to it. Health becomes a task that needs the patient’s active and conscious participation, being he/she the first one responsible for his/her well-being. Co-operation, which is central to doctors and nurses, as well as frequent hospital attendance lead the patient to perceive himself/herself in a medical way, to think of him/herself in terms of weight and pressure. They refer to themselves using a medical language and parameters: for example when they are asked about their conditions, usually they answer speaking about themselves in terms of increasing or decreasing of weight, using typical expressions, such as “porto tot. peso”, meaning that between treatments their weight – “peso” in Italian – has increased or decreased.

At the same time, patients are asked to be very careful when moving the arm where the fistula is ‘built’. They should do daily activities, but avoid those that could cause haemorrhage, like

¹⁵ For a critical point of view about the notion of “good patient” between autonomy and compliance, see, for example, FAINZANG, 2010.

wearing tight clothes, watches or bracelets that could decrease the arm's blood circulation. The arm has to be constantly monitored by the patient, who has to pay attention to skin alterations and to verify constantly, through tapping, that the fistula is not obstructed. The patient has to monitor this body's modification that allows him/her to communicate with the machine, since the fistula can be closed and if this happens it has to be reopened. The body has to be listened to and monitored daily, since it is constantly at risk. It is the object of a life project, which delegates to the person the responsibility of his/her well-being. The sick person has to acquire therapeutic competences through an education to be a patient; he/she has to manage his/her life-style and diet. A dietician usually suggests to the patient an appropriate diet, in accordance with some common rules. In particular, doctors recommend monitoring liquid assumption, to avoid water retention. When the kidneys are not working properly, the patient does not urinate almost at all. In case of weight increase, therapy becomes difficult for the patient, who may be subject to nausea, heart failure, hypertension or lung oedema. Patients should avoid drinking alcohol or eating fruits, vegetables, fatty foods, cheese. Food is thus thought of in terms of its components: phosphorous, sodium, potassium and so on. Food becomes like a horrible beast, as one of the patient has defined it, confessing also to "be scared of potassium". It is the patient's very life style that has to be adapted to the therapy in order to improve significantly his/her condition, while he/she learns how to deal with his/her sick body. He/she has to learn how to preserve his/her body, since haemodialysis allows he/she to survive only by substituting the damaged renal functions.

In this process of adaptation to the therapy, the support of family and friends is fundamental. They help patients in performing daily activities. However, patients try to be as autonomous as possible, even in regards to their husband or wife and children, and they are frightened by the possibility to be turned into a burden for their family in case of a worsening of their condition.

Especially in the cases of very old patients unable or unwilling to adapt to the limitations imposed by the therapy, the family urges them to continue to undergo treatment and supervise adherence to the diet. For example, Carmine, a 85 year old man, who has

recently started treatment, cannot understand why his situation is worsening rather than improving. The haemodialysis, in fact, provides for a gradual adaptation: the duration of treatment – that initially for Carmine was about two-and-a-half hours – increases slowly during the first few sessions to reach, usually, four hours. Such an increase in the time of treatment is associated by Carmine to a worsening of his health and dishearten the man regarding the actual usefulness of the therapy. Thus, he is reluctant to live with the limitations imposed by haemodialysis. Although he is continuing to regularly attend the ward in order to satisfy the insistence of his wife and sons, he tell me: “Sometimes I eat bread, butter and anchovies, but secretly!” When I ask him who he is hiding from, he reply: “From my wife, of course!”

Strategies

Haemodialysis is a very invasive treatment and it is very risky for the patient’s life. The patient him/herself may not understand every step of the therapy, but he/she has to participate while relying on doctors and nurses, which demands total trust. This sense of surrender of the patient, which is considered necessary by technicians, is twice hindered: on one hand by the strict relationship between doctor, nurse and patient who are very close during the therapy, this proximity makes technicians observable and, therefore, understandable to the patients; on the other hand, by the patient’s necessity to regain control over his/her life.

As demonstrated for other types of patients, like oncological ones¹⁶, sometimes the side effects of certain therapies have such relevant burden on the person’s life to attract the aggressiveness previous directed to pathology, and to become themselves an illness. Haemodialysis is intended and represented in most of the patients’ accounts as a negative element in their life: they know it is necessary for their survival, nevertheless it is seen as something that they are forced to adapt to. The limitations that this kind of

¹⁶ MARZANO and ROMANO, 2007.

therapy imposes are perceived by patients as “a cause of suffering that kills slowly”.

Patients have few ways to redeem their condition of illness and of dependence: by taking possession of themselves, “stealing” rudiments of medical thought, and by trying to be independent during the therapy, in particular for what concerns common gestures. Indeed, haemodialysis constructs its own subjects in contradiction: patients ask for somebody that they can rely on and trust, but, not being able to live as sick people, they need to find strategies to rethink themselves as ‘other’ from the therapy. In this way, patients seem to redefine their own spaces, their individuality, in contrast with those of nurses, trying to distinguish between the dependence that they are submitted to, since they do not have medical knowledge, and the dependence that is induced by the very therapy. During the treatment, patients tend to be as independent as possible, avoiding asking for nurses’ assistance, and helping themselves with their free hand and with the mouth to open a pack of biscuits or candies. In this sense, I can interpret patients’ request to turn the monitor of their machines towards them, so that they can autonomously control and evaluate their values. In one occasion, the patient’s attempt to be autonomous has induced a doctor to regain the control of the therapeutic encounter. Hindered in his work by an artificial kidney moved by request of the patient, the doctor has tried to limit the ‘invasion’ into his field, inviting him to focus on those activities (TV, reading, etc...) that could help to pass the four hours¹⁷ time instead.

The long period of time passed frequenting the health facility leads the patient to learn certain medical terms. As a result, he/she becomes more familiar with his/her treatment. In some occasions, nurses ask patients about their specific therapy, without even checking it (for example, the time a patient has to spend connected to the artificial kidney). In general, though, it is the patient that is interested in learning rudiments of the techniques that keep him/her alive. He/she is able to manage him/herself, if he/she gains extra weight between therapies it is

¹⁷ The duration of the therapy.

not because he/she does not know the food composition, but because sometimes he/she doesn't want to be submitted to the rules and the obligations imposed by the therapy¹⁸. By evading rules or manipulating the contract¹⁹ with health professionals, patients seem to build their own agency, claiming their right to know what is best for themselves. As nurses know some "tricks" to allow to the artificial kidney to overcome periodical security tests to which they have to be submitted, through their own personal perception and evaluation of the risk, so patients negotiate what is best for them making their own evaluation of the eventual risk they have to face. One of them, for instance, declaring that he constantly felt cold during the therapies, and knowing that the nurses would not raise the temperature of the blood introduced again in the body all at once, whenever one of the nurses approached his bed he asked to increase the temperature of half Celsius degree, obtaining in this way his scope by tricking the nurses. In this way, the patient contributes to the construction of himself, getting around biomedical constraints, avoiding nurses' convictions and recovering the right to know what is better for him, still in biomedical terms. Through this specific language of biomedicine as a cultural system, the patient recovers himself as an active subject and opens up a space for himself.

However, the most striking aspects of the haemodialysis therapy are the structure of the space in which the treatment takes place and the collective character of it. These aspects allow the patients to be reciprocally visible and to interact, thus recovering the social aspect of the medical encounter. Sharing the treatment makes the group an important tool for patients. Through daily dialogue, they help each other in dealing with their illness and in learning new information, for instance increasing those given by the dieticians. Reciprocal understanding and support, as well as reassurance concerning their condition and health seeking behaviours are fundamental. In this sense, the "peer" group in the haemodialysis treatment can be considered as a useful tool of

¹⁸ About dietary transgression, see also KUTNER, 1987 and DOUGUET, 2000.

¹⁹ TAUSSIG, 1980.

mutual aid, through which patients increase their wellbeing and become more conscious of ways to deal with a chronic illness²⁰.

Within this journey, even imagination seems crucial as a creative ability to construct a new self, which configures itself as medicine, tool for recovery and reacquisition of the personal body²¹. The ability of narrative re-elaboration, as a tool through which the person integrates his/her experience of suffering in his/her own history, allows the patient to make sense of the illness. Many patients have told me about the deprivations of their own childhood, highlighting how they were not scared of limitations, almost convincing themselves of the possibility of overcoming their present situation: imagination becomes then a dialogical moment. It is a complex work on him/herself that the patient has to perform, whereby the self-comprehension through narration is fundamental. Through narration, the patient rebuilds the sense of his/her own personal story²², and is able to think about a future perspective. In the narration, the patient recognizes him/herself and thinks about him/herself in a progressive order, interrupting the cyclical time within which he/she is constrained by haemodialysis.

Some patients say that they perceive the therapy “as if” they were going to the gym, or to work. After all, they say, “we spend lots of time earning money, can’t we invest some of it to continue living?”. It seems possible to argue that the metaphorical process performed by patients becomes the tool through which they are able to justify an otherwise meaningless experience. The metaphor is then the very tool to manipulate the experience, which transcends logical constraints, and through which the patient reconstructs his/her normality²³. It also may be possible to argue that the patient, through the creative use of his/her own history and the support of imagination, recovers a space of resistance and becomes, as De Certeau (1980) puts it, a creative

²⁰ About the role of the peer group, see also DOUGUET, 2000.

²¹ KIRMAYER, 2006.

²² GOOD, 1994.

²³ KIRMAYER, 1992.

consumer of the practice, trying to take possession of it because of the impossibility of avoiding it.

References

- ALEXANDER, Linda (1981) "The double-bind between dialysis and their health practitioners", In LEON, Eisenberg, and KLEINMAN, Arthur (eds.) *The relevance of social science for medicine*. Reidel: Dordrecht.
- BACHIMONT, Jeannine (1998) "Les "soins hospitaliers à domicile" entre démedicalisation hospitalier et médicalisation du domicili", In PIERRE, Aïach and DELANOË, Daniel (eds.) *L'ère de la médicalisation: ecce homo sanitas*. Paris: Anthropos.
- BURY, Michael (1982) "Chronic Illness as Biographical Disruption", *Sociology of Health and Illness* 4 167-182.
- BURY, Michael (2005) "Sulla malattia cronica e la disabilità", In PAOLA MARIA, Fiocco and MORI, Luca (eds.) *Salute e Società. La disabilità tra costruzione dell'identità e cittadinanza*. Milano: Franco Angeli.
- CHARMAZ, Kathy (1983) "Loss of self: a fundamental form of suffering in the chronically ill", *Sociology of health and illness* 5 168-195.
- CHARMAZ, Kathy (1991) *Good Days, Bad days: The Self in Chronic Illness and Time*. New Brunswick: Rutgers University Press.
- COMAROFF, Jean and MAGUIRE, Peter (1981) "Ambiguity and the Search of Meaning: Childhood Leukaemia in the Modern Clinical Context", *Social Science and Medicine* 15b 115-123.
- DE CERTEAU, Michel (2001) *L'invenzione del quotidiano*. Roma: Edizioni Lavoro. [or. ed. 1980].
- DOUGUET, Floraence (2000) *De la passivité à la gestion active du traitement de sa maladie*, Paris, L'Harmattan.
- ESTROFF, Sue E. (1993) "Identity, Disability and Schizophrenia. The Problem of Chronicity", In LINDENBAUM, Shirley and LOCK, Margaret (eds.) *Knowledge, Power & Practice. The Anthropology of Medicine and Everyday Life*. Berkeley: University of California Press.

- EUGENI, Erica (2008) "Come parlano i corpi secchi: narrazioni di malattia in emodialisi a Roma", *Linee di sangue. "Metafore e pratiche tra dono, filiazione e appartenenza"*, *Erreffe. La ricerca folklorica* 58 59-66.
- EUGENI, Erica (2009) "Vivere da malato: sorveglianza e resistenza", *Etnografie: immagini della pratica etnografica, Rassegna italiana di sociologia* 1 49-74.
- FAINZANG, Sylvie (2010) "Qu'est-ce qu'un bon patient? Un patient autonome, mais pas trop...", in CRIGNON-DE OLIVEIRA, Claire and GAILLE, Marie (eds.) *Qu'est-ce qu'un bon patient? Qu'est-ce qu'un bon médecin? Réflexions critiques, analyses en contexte et perspectives historiques*, Paris: Seli Arslan 106-116.
- FRANK, Arthur W. (1995) *The Wounded Storyteller. Body, Illness and Ethics*. Chicago and London: University of Chicago Press.
- GOOD, Byron. (1994) *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- HONKASALO, Marjia-Liisa (2001) "Vicissitudes of pain and suffering: chronic pain and liminality", *Medical Anthropology* 19 319-353.
- KIRMAYER, Laurence J. (1992) "The body's insistence on meaning: metaphor as presentation and representation in illness experience", *Medical Anthropology Quarterly* 6 (4) 323-346.
- KIRMAYER, Laurence J. (2006) *From imaginary medicine to the medicine of imagination*, paper presented at CASCA, Concordia University, Montreal.
- KUTNER, Nancy G. (1987) "Social Worlds and identity in end-stage renal disease (ESRD)", *Research in the Sociology of Health Care* 6 33-71.
- LOCK, Margaret and GORDON, Deborah (eds.). (1988) *Biomedicine examined*. Dordrecht: Reidel.
- LOCK, Margaret, YOUNG, Allan and CAMBROSIO, Alberto (2000) *Living and working with the new medical technologies*. Cambridge: Cambridge University Press.
- MARZANO, Marco and ROMANO, Virginia (2007) "Cronicità e normalità nei racconti dei malati di cancro", *Rassegna italiana di sociologia* 1 57-89.

- RABINOW, Paul (1996) "Artificiality and enlightenment: from sociology to biosociality", in Id. *Essays on the anthropology of reason*. Princeton: Princeton University Press.
- RUSS, Ann J., SHIM, Janet K. and KAUFMAN, Sharon R. (2005) "Is there life on dialysis?: Time and aging in a clinically sustained existence", *Medical Anthropology* 24 (1) 297-324.
- TAUSSIG, Michael T. (1980) "Reification and the consciousness of the patient", *Social Science and Medicine* 14b 3-13.
- VAN DONGEN, Els and REIS, Ria (2002) "Editorial chronic illness: struggle and challenge", *Medical Anthropology* 19 293-297.

INVISIBLE CHRONIC ILLNESSES *INSIDE* APPARENTLY HEALTHY BODIES

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Introduction: invisible chronic illness

This paper aims to contribute to medical anthropology research on how the invisible chronic illness experience and social treatment of the body are inextricably configured both culturally and biomedically. The ethnographic material was collected in Catalonia (Spain) and is part of an ongoing research on chronic illness for my PhD studies in medical anthropology. Data presented here were obtained through in-depth semi-structured interviews, observation, personal illness narratives published on the web, autobiographical books on the illness experience, personal accounts and experiences, and some relevant scientific literature on the subject. The verbatim quotations selected aim to summarize or to be representative (at least significant, as a first approach) of the invisibility-visibility problem and paradox concerning the chronic illness experience. The context for this discussion is applied to Western, industrialized and medicalized settings, at the present moment².

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² Other socio-cultural contexts and historical moments, where illness meanings and beliefs may differ, are not intended to be discussed here as they go beyond the scope of this paper.

The first question to address is: what is an invisible illness? *Invisible illnesses* may be defined as illnesses that are not readily seen (noticeable), but do exist. This is a paradox: they are not physically apparent but they physically exist? In what ways, how and why is an illness visible or invisible? Who decides whether it exists or not? To say that something exists, and is therefore real, refers us to the concept of 'illness reality', understood either as a cultural category (GOOD³, 1977; WARE 1992) or as a biomedical nosology (ICD-10). The second question to address is: what are the consequences of visibility or invisibility for the sick people? How does it affect their daily life, their social relations and interactions? This article addresses the problematic of delegitimation of the body-self⁴ and of the illness experience, the way stigma and social rejection threaten to compromise the individual's identity, and the neglect of care needs and suffering, through four constructs proposed here as analytical categories that will provide insights into the paradoxical situation of 'healthy-sick' bodies: physical invisibility, social invisibility, medical invisibility and political invisibility. These four dimensions should not be understood as independent, but rather as a continuum on which the chronically ill experience the issue of invisibility-visibility.

Although the consequences of invisibility may affect most chronic illnesses⁵, some characteristics specific to some types of illnesses, sufferings or unwellnesses⁶ raise a particular problematic.

³ Illness reality defined as "a 'syndrome' of typical experiences, a set of words, experiences, and feelings which typically 'run together' for members of a given society, a set of experiences associated through networks of meaning and social interaction" (GOOD, 1977:27, see also GOOD and GOOD 1982)

⁴ In the sense of a phenomenally experienced individual body (SCHEPER-HUGHES and LOCK, 1987)

⁵ However, this is not the case of all illnesses; depending on the course the illness takes, clear signs of sickness may or may not be visible.

⁶ The three terms are used deliberately because, although they may seem to be synonymous, they can also have different cultural and biomedical meanings with regard to the illness experience. Focussing the discussion on known chronic illnesses, the term *illness* will be used to refer to all three terms, to avoid constant repetition. The other two terms will be used when specifically needed.

While these are clearly not closed areas, I have made a preliminary classification of some chronic illnesses that share certain traits in order to show how their characteristics go beyond general aspects. Biomedical nosology is a necessary starting point for this classification, where we can identify five chronic illnesses groups that share some similarities according to their social and biomedical perception.

1. *The 'not real' ones, that cause disbelief*: the so-called 'new illnesses' such as Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM) and Multiple Chemical Sensitivity (MCS), and other forms of chronic pain of unknown etiology, whose main problem is social and/or medical delegitimation of the body-self and of the illness experience.
2. *The 'nonexistent' ones, that arouse suspicion*: illness processes that have no specific diagnosis⁷, multiple unexplained symptoms (MUS⁸) and other long term sufferings or unwellnesses that still do not fit into any known biomedical diagnostic category. As with the first group, their main problem might be social and/or medical delegitimation of the body-self and of the illness experience.
3. *The common ones*: biomedically and socially well established and more prevalent nosological entities such as hypertension, diabetes, celiac disease, hepatitis C, etc. Apparently these illnesses might not entail social or medical delegitimation of the illness itself, but rather a

⁷ Biomedical nosology uses the term *illnesses without a specific diagnosis*, although I prefer to call it *illness processes without a specific diagnosis* to emphasize the process of suffering or unwellness. The terms *unspecific diagnosis* or *non-specific diagnosis* are also accepted in biomedicine, which is a paradox, since it is *unspecific*, there is no diagnosis to refer to. This word play shows the supremacy of biomedical nosology in a medicalized context, and how it legitimates illness processes by 'discovering' and naming/labelling them.

⁸ Or *medically unexplained symptoms*. Both are abbreviated as MUS and are widely accepted by the scientific community.

delegitimation of its experience and of the sick person according to a social status of illnesses.

4. *The 'unmentionable' ones*: mental illnesses, generally neurotic disorders⁹, whose main problem is disclosing them (the question of secrecy) because of the threat of stigma and social rejection that they may cause.
5. *The 'unknown and neglected' ones*: the so-called rare diseases (RD) that because of their low prevalence are ignored by society and overlooked by public policies.

A few chronic illnesses are 'body-external' clearly visible from a trace or a sign that identifies the person as sick. However, many illnesses are not visible to the others' gaze. Paradoxically, illness visibility or invisibility does not only depend on a visual verification of observable evidence, but on a social gaze that combines illness cultural meanings and beliefs. Similarly, it can be argued that invisibility does not only depend on the illness itself, if illnesses are not considered to be naturally invisible, but socially or medically invisibilized. An anthropological approach to the subject through the invisibility process should allow us to demonstrate this argument by following a sequence of combined steps/actions: to see or not, to know or not, to recognize or not, and to accept or reject.

Physical invisibility: presumption of health and secrecy

The very first step is the visual aspect. Adapting a well-known phrase from Shakespeare: "To see or not to see, that is the question" (as a first step). Many chronic illnesses do not necessarily involve, at least not permanently, an obvious change or physical deterioration that might indicate to others that somebody is sick. At first glance, therefore, others (the social gaze) may mistakenly think a sick

⁹ Psychotic disorders are thought to be less invisible because they may be easily detected through body language such as facial expression, visual contact, spatial movements.

person is healthy, by conforming to socially accepted ideas about the healthy body – appearances, of course, can be deceptive. If visual verification does not indicate the contrary, people might assume that someone is ‘healthy until proven sick’¹⁰.

The social ideal of an apparently healthy body that leads to physical invisibility may also result from unawareness of a person’s illness condition. In this case, “to know or not to know” is the question (second step). How do we find out that somebody is sick if it is not visually obvious? In most cases, the sick person informs us¹¹. This is related to the recognition action (third step) in the sense of recognize oneself truthfully, according to one’s abilities or weaknesses. In this case, those socially ‘presumed healthy’ might be sick, but may not be wanting to admit to or inform others about their illness condition. In attempting to hide the fact that they are sick, they are deliberately invisibilizing their condition, both physically and socially, trying to pass off as ‘normal’ or ‘healthy’ (HAY, 2010; MILES, 2005; WARE, 1992; WARE and KLEINMAN, 1992). The preference for hiding or disclosing is related to the individual’s control of information and self-identity (GOFFMAN, 1995), as well as to the social status of their illness (MASANA, 2008). Secrecy is an individual decision motivated by the fear of compromising one’s identity, under the threat of being stigmatised, socially rejected or excluded, among other reasons concerning family, social or work problems¹² that could arise. Stigma, rejection and delegitimation cause moral and social suffering (GOFFMAN, 1995; KLEINMAN 1988, 1995; KLEINMAN and BENSON, 2004) and can entail feelings of guilt, frustration, shame, humiliation or vulnerability. Fear of these consequences may explain why even those with a biomedically

¹⁰ Comparable to the legal term ‘innocent until proven guilty’. Likewise ‘presumption of health’ as an analogy of ‘presumption of innocence’.

¹¹ We can also find out about somebody’s illness through others, but this issue will not be discussed here.

¹² In this article I do not consider what might be termed *labour invisibility*, which can arise when social and medical delegitimation restricts the work options of those for whom the constraints of chronic illness make a full-time job impossible. A further analysis on this type of invisibility would be desirable.

and socially well established nosological entity – common illness – may prefer to hide their situation. If those who opt for secrecy manage to ‘pass off’ as healthy by keeping others in the dark about their illness situation, physical and social invisibility is guaranteed and some problems may be avoided. A woman in her forties suffering from four invisible chronic illnesses with mild-moderate limitations, decided not disclosing her illnesses conditions for avoiding work problems:

I don't want to let them [work colleagues] know. I don't want to have problems at work. I don't want to risk losing my job. It was hard to get where I am now [current job position]. I can not resign. (...) And the work is very demanding. I have a lot of work and stress, but I can not do otherwise.

This woman's desire to keep her illnesses secret and to continue working as ‘normal’ offers an example of what HAY (2010) calls the *‘John Wayne model’*, a coping strategy for chronic illness grounded in a cultural expectation of productivity. This strategy entails continuing to meet all ‘normal’ societal demands, not letting the limitations caused by the illness get you down, in a way ‘ignoring’ that you are ill. But this approach also has its price and takes its toll on the health situation (HAY, 2010; MILES, 2005). When asked about her health and work priorities, she answers:

I don't know.... Well, objectively the priority is health, without health you don't do anything. But, I am actually really into my job. May be I don't take enough care of myself. I work more than what I should... I don't know, I should take better care of myself, because without health you don't have a life. I know, but maybe I don't do anything for... I don't take a decision. I would like to reduce my working day, work less hours, or find another job. But I don't change. I am so used to this pace of work that I don't realise that I can't [physically/continue like this]. Work is really demanding. You must pretend that nothing is happening, but it is!

Secrecy may allow sick people to avoid stigma, rejection, disbelief, delegitimation, guilt, shame, etc., but it also prevents them from receiving social support from their networks (who do not know they are sick). This support can come in many different forms: at a medical level (drugs or food control), at a practical level (logistical support) such as help with shopping or housekeeping,

or at a moral/emotional level, which means being there (able to do whatever) for your relative or friend (to listen, talk, go for a walk, etc)¹³ (MASANA, 2010). Moreover, and paradoxically, secrecy as a protective cover can be counterproductive (non-protective), by entailing risks when the appropriate healthcare response is not forthcoming when needed, in the case of an epilepsy attack or hypoglycaemia for instance. In contrast, when the ill person discloses and therefore informs¹⁴ others about his/her illness situation, it allows also to explain how others should (re)act if something goes wrong.

Although keeping the illness secret and trying to pass off as 'normal' is an attempt to avoid the effects of stigma, it does not completely prevent social rejection or isolation. Hiding the constraints and needs of an illness is not easy, because sometimes the illness situation will prevent sick people from 'passing off' as healthy. As a result they may occasionally neglect their social duties, causing a lack of understanding in others. If this happens regularly, it can lead to social isolation because neglecting social duties compromises the durability of social relationships (GOFFMAN, 1995; KLEINMAN, 1988; MILES *et alii* 2005). In addition, hiding the constraints on activity (what people could do) when others are unaware of its existence, can lead to misunderstandings and prejudices, because of the socially accepted ideas about what is considered to be 'normal capacity' to carry out several daily or social activities (JOHANSSON *et alii*, 1999; MILES *et alii* 2005); for example: standing up on a bus or asking for a seat, using stairs or taking the lift, going for a short walk or for a long distance or trekking day, needing a daily nap after lunch, etc. Sick people will be required to justify or to explain 'why' or 'why not' they do so (risking disbelief due to their healthy appearance); or they may try to avoid such situations, thus compromising their social life. In

¹³These three levels of attention come from a central subject of discussion in my ongoing dissertation. Further explanations can be found in MASANA, 2010.

¹⁴As CHARMAZ (1991) understands it, "informing differs from disclosing in that the informer does not feel risk, takes an objective position and makes an announcement about the condition" (quoted in JOACHIN and ACORN, 2000).

contrast, by letting others know about their illness situation, and with a desirable level of social acceptance, sick people can retain their social presence, normalize their social contacts with those who are aware of the whole situation, and restore their life-world (*lebenswelt*¹⁵) despite illness constraints.

*Social invisibility:
delegitimation of body-self and of the illness experience*

Recognition (third step) implies another different action and meaning: being recognized by others in the sense of accepting something as true or real. When those who are sick decide to admit and inform others about their illness situation, and do not hide it in order to 'pass off' as healthy, they can meet with two basic reactions: acceptance or rejection (the fourth and last step). Although on the whole, sick people would prefer acceptance, when asked, ethnographic data show that at times, publicly recognizing their illness situation compromises their individual and social identity. The so-called 'healthy until proven sick' may become 'guilty of being proved sick'¹⁶. Sickness is a moral experience to which recognition is a moral response (moral act, KLEINMAN and BENSON, 2004). Social rejection perpetuates social invisibility, as the consequence of disbelief in or non-acceptance of a known illness situation, either because of an apparently healthy appearance or because of the type of illness. In other words, the phenomenon of 'not wanting to see, nor to recognize, nor to accept, despite knowing' which entails the delegitimation

¹⁵ In the phenomenological sense of HUSSERL (1991): the illness experience is one of destruction and construction of the individual's life-world.

¹⁶ Socio-cultural construction of illness is linked in some cases to a moral prejudice: being guilty of being sick. The Spanish dictionary (RAE, *Real Academia de la Lengua Española*, 22ª edición) defines the verb *reconocerse*, to recognise or acknowledge, as "to confess (admit) to having committed an error, a fault, etc". In this case the illness could be the error or the fault, understood as a deviance from what is considered to be 'normal' (see sociology of deviance, and symbolic interactionism; BECKER, 1964; GOFFMAN, 1979; GOFFMAN, 1995; PARSONS, 1999)

of the body-self and of the illness experience, as is clearly evident from the following list of *sentences* (in both the grammatical and legal sense) that shows how social rejection operates according to the combined actions (steps) mentioned above: *a)* Seeing or not: “But you look good/You look too good to be sick /Well, you don’t look sick.”; *b)* Knowing or not: “Well, it is not noticeable./Nobody will know that you are sick.”; *c)* Recognising or not: “But you don’t act sick./ You’re just having a bad day.” and *d)* Accepting or not: “It must be nice not having to go to work./ I wish I had time to take a nap./ It can’t be that bad./Aren’t you exaggerating?/ There are people worse off than you.” Most, if not all, of these delegitimation *sentences* and their effects on the sick person can be found repeatedly in the narratives of the chronically ill¹⁷. A woman in her thirties who suffers from multiple unexplained symptoms together with chronic (physical) pain, expresses how disbelief and delegitimation entail moral consequences such as *moral pain*:

Just as pain is perceptible and real for those who suffer, it is intangible for ‘those that don’t know what pain means’, for those who have never experienced and felt that kind of pain. And my pain isn’t only physical; it’s also moral, because others don’t believe my pain is real.

The concept of delegitimation is used in this paper to refer to the ‘loss of a legitimate world’ (KLEINMAN, 1992), which implies cultural values and norms about what is considered to be ‘normal’. An anthropological approach to social invisibility refers us to the social construction of illness through cultural meanings and beliefs (WARE, 1992; WARE and KLEINMAN, 1992). Any illness must

¹⁷The representative and repeated verbatim come from the ethnographic data sources explained above. Significant examples of internet narratives from blogs or associations of sick persons (represented here) include “*An open letter to those without invisible disability or chronic illness...*” (<http://notdoneliving.net/openletter/id>, accessed February 25, 2011) and “*Warning: Things not to say to someone with a disabling chronic illness*, (in www.chronic-illness.org , accessed February 25, 2011)

be recognized socially and culturally¹⁸ (not just biomedically) to be accepted as 'real illness'. If not, illness is 'nonexistent' and will not be recognized, thus the body-self identity will be disbelieved and the illness experience delegitimized. Moreover, the social construction of illness implies a kind of 'ranking' within chronic illnesses, attributing moral values such as 'good or bad reputation' illnesses (MASANA, 2008): high status illnesses are considered to be really 'important' or severe and must be taken seriously – cancer, hypertension, etc –, in contrast to low status 'B-list' illnesses – chronic fatigue syndrome, fibromyalgia, etc. – which tend to be discreditable or discredited (GOFFMAN, 1995). This classification lends a socio-cultural status to the illness and to the sick person that is directly related to the social response – recognition, acceptance or rejection, legitimation or delegitimation – to the illness, to the sick person or to both.

Social invisibility is closely linked to medical invisibility: as mentioned above, social treatment of the body is inextricably configured both culturally and biomedically. Although in some cases biomedical nosology can be secondary to cultural categories of illness, in other cases (today, mainly in a medicalized Western context) the biomedical paradigm have an important influence on cultural values, affecting and even transforming them. The following discussion shows how medical invisibility and delegitimation has its correspondences with social invisibility and delegitimation.

Medical Invisibility: looking for the truth

Medical invisibility mainly results from the lack of biomedical diagnosis or the absence of observable evidence of pathology. If aetiology is unknown and diagnosis unspecific, so do are treatment and prognosis. In biological terms, this medical invisibility is a variation of the first physical invisibility mentioned above, where the medically trained eye (professional) or the most advanced

¹⁸ See COMELLES and MARTÍNEZ, 1993; COMELLES and PERDIGUERO 2000; KLEINMAN, 1980.

diagnostic tests (and technology) ‘can not see’ the illness. The main points to address are ‘who is looking at whom?’ and ‘who is assessing the illness experience?’ On the first and second categories we referred to the social gaze only, but in this third category the gaze and assessment come from both: social agents and health professionals.

In some cases, hegemonic biomedicine ‘can not see and can not know about’ some illness processes or sufferings. This presents an odd paradox today, since advances in medical technology – body-image treatment: NMR, ACT, X-ray, etc. – have visibilized many diagnoses and nosological entities, which were hitherto unknown. This enable to bring visibility to some illnesses that were not previously known as *illnesses*, and thus not recognized by either the scientific community or society as a whole (and therefore nonexistent?). However, here is where the paradox lies: advanced diagnostic techniques are continually coming up against illnesses, sufferings or unwellnesses that resist biomedical identification and visibilization: “One must have laboratory signs in order to be suffering; one must suffer in code [ICD-10] in order to be suffering in fact, or one does not suffer at all” (DUMIT, 2006:580). This poses the question of the illness reality and existence, which might raise suspicion and cause disbelief, thus leading again to the delegitimation of the illness experience. The paradigmatic examples of medical invisibility are: 1) the so-called ‘new illnesses’, those classified at the start of this chapter in group 1, such as chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity¹⁹ and chronic pain; 2) illness or suffering processes with no specific diagnosis and multiple/medically unexplained symptoms (MUS), classified in group 2. Both entail physical and social invisibility, but also medical and political invisibility (as we will further see).

The so-called ‘new illnesses’, such as chronic fatigue syndrome or fibromyalgia, are placed in an ambiguous status of illness within the medical community, where professionals are still divided and

¹⁹ Some recent scientific researches have found (through NMR) some physical evidence of its existence, in the form of brain activity, but MCS is still not widely recognized and still has no ICD-10 code.

have yet to reach a consensus about their 'real existence'. The absence of observable evidence of pathology (sign) leads to the assumption that they are, in fact, mental/psychological disorders or psychosomatic illnesses (manifested through various symptoms) (DUMIT, 2006; KLEINMAN, 1988; SCHEPER-HUGHES and LOCK, 1987; WARE, 1992, 1993)²⁰. Similarly, in illness processes with no specific diagnosis (and MUS) if physical evidence resists identification, then mental, psychological or psychosomatic explanations are given (DUMIT, 2006; JOHANSSON *et alii*, 1999; NETTLETON, 2004, 2005). However, the debate among health professionals over the 'real existence' of this second group of illnesses differs in that there is no defined nosological entity to discuss. In both illnesses groups, biological 'nonexistence' in the eyes of the medical community (sign) might entail the delegitimation of the illness experience (symptom) and lead to the stigma associated with the label of mental disorder or psychosomatic illness (WARE, 1992), an assumption that sick people are reluctant to accept as valid or, at least, as the only one. This shows how the invisible chronic illness experience and the social treatment of the body are inextricably configured both culturally and biomedically in a medicalized western society. The biomedical assumptions and definitions of illness are embodied by individuals, whose cultural meanings for psychosomatic illness are that its symptoms are 'imagined' (DUMIT, 2006; JOHANSSON *et alii*, 1999; NETTLETON, 2004; WARE, 1992;) or 'created' by the sick people themselves: "It's all in your head./ You're bringing this on yourself. / You just need a more positive attitude". Such assertions lay the blame on the sick people by making them responsible for their suffering and illness situation²¹. Although they accept the authenticity of their symptoms, being

²⁰ "(...) in psychosomatic medicine there is a tendency to categorize and treat human afflictions as if they were either wholly organic or wholly psychological in origin: 'it' is *in* the body, or 'it' is *in* the mind (SCHEPER-HUGHES and LOCK, 1987, emphasis in the original)

²¹ Blaming the sick is not, however, exclusive to those suffering from 'new illnesses' or MUS, but also for those with a well-established nosological entity, such as cancer, through what is known as 'cancer-prone personality' (DiGIACOMO, 1992).

repeatedly disconfirmed by others in their definition of 'illness reality', together with plus the absence of biomedical proof or physical explanation lead some of them to self-doubt (WARE, 1992). A woman in her fifties who suffers from chronic fatigue syndrome and from familiar and social disbelief about her illness, wondered: "Is it my nerves, after all? It is all in my head? Am I going crazy? Am I just imagining it?"

Delegitimation of the illness experience means hearing that they do not look sick, that their complaints are exaggerated, that their illness is not real or nonexistent, that all is in their mind, etc. Words such as 'fraud', 'false', 'hypochondriac', 'hysterical', and so on, are inextricably linked to accusations of malingering, with the underlying assumption that they are not really ill (DUMIT, 2006; JOHANSSON *et alii*, 1995). Delegitimation through trivialization of symptoms increases self-doubt (WARE, 1992) and self-blame (DUMIT, 2006; JOHANSSON *et alii*, 1995), generates anxiety and increases moral suffering (KLEINMAN and BENSON, 2004). The sign-symptom dilemma within the biomedical paradigm presumes the non-acceptance of biomedical limitations, and causes disbelief, suspicion and lack of understanding of what can not be proved. Biomedical objectiveness, however, does admit the difficulties of assessing symptoms that are subjective in nature (such as pain or fatigue), and therefore not easily measured by tests. Similarly, the same suspicious or sceptical biomedicine is trying to run 'evidence based' approaches to the above mentioned functional illnesses or syndromes like chronic fatigue syndrome or fibromyalgia, through cognitive behavioural therapies, randomised drug trials, etc. On the other hand, the professionals who do believe these illnesses to be real are determined to prove their existence objectively through tests. These types of illnesses are, therefore, partially visible to society and the medical community- we/they know about them - but, they are still a long way from being 'seen', as in recognized, accepted and legitimised.

Medical invisibility, moreover, has other consequences for people with medically unexplained symptoms (MUS) and/or suffering processes without biomedical diagnosis. In an attempt to find the 'truth', sick people are caught up in an endless round of (pilgrimage through) doctors' appointments and tests, in

pursuit of an explanation for their unwellness that might lead to diagnosis and treatment (ASBRING and NÄRVÄNEN, 2004; DUMIT, 2006; NETTLETON, 2005). Paradoxically, they experience ambivalent feelings: on the one hand they do not want to be ill or to be blamed for having a psychosomatic illness that others regard as self-inflicted, but on the other hand, they tirelessly seek out observable biomedical evidence that would give a 'name' to their suffering. Their aim in doing so is to restore their credibility through biomedical legitimization, in order to be recognized as sick and have the right to be cared for (ASBRING and NÄRVÄNEN, 2004; DUMIT, 2006; JOHANSSON *et alii*, 1999; MASANA, 2010).

Biomedical failure on these kinds of illnesses has left sick people feeling betrayed and neglected²² (KLEINMAN, 1988, 1995), and with no means of coping (WARE, 1992). In their pursuit of a solution, many of them try their luck with non-conventional medicines (ASBRING and NÄRVÄNEN, 2004), the so-called *complementary and alternative medicine* (CAM²³), the results of which are not always satisfactory or efficient. In addition, social disbelief and lack of understanding about certain illnesses seems to encourage others to offer therapeutic advice (VALVERDE, 2009). Somehow they play 'doctor's-role', in an attempt to diagnose or suggest treatments telling advices to the sick people on what should they do, under the slogan "it worked wonderfully for me" or "I knew someone who had something like you, and got better". VALVERDE (2009) reports a selection of these pieces of advice in her autobiographical book on chronic fatigue syndrome experience:

²² This is a recent phenomenon (last decades) resulting from the medicalization process, whose hegemonic paradigm has been embedded in beliefs and practices related to health/sickness/care processes. Individuals come to depend extensively on health professionals to cure and care for their suffering. Failure to meet the high expectations of today's western society is understood as betrayal and neglect by those who should take care of our health.

²³ There is still no consensus about how to categorise these healing practices of unconventional medicine, although *Complementary and Alternative Medicine* (CAM) is the most widely accepted term (PERDIGUERO, 2004).

Acupuncture will cure it. / Have you tried Feldenkreis? / What you need is reflexotherapy. / Tai Chi will make you better. / I know a healer that cures with African plants. / Have you tried a vegetarian diet? / What you need is colour therapy. (VALVERDE, 2009:68)

Hopelessly sick, some people turn to these non-conventional therapies and accept treatments with sometimes unknown adverse effects; however, their fears diminish in their quest for a solution to their problem²⁴, a quest that unfortunately has no guarantee of success.

Medical invisibility, together with the failure of biomedical and non-conventional treatments, increases feelings of uncertainty about the illness, its course and prognosis, its consequences and its threat to one's life (JOHANSSON *et alii*, 1999; KLEINMAN, 1988). This combination brings uncertainty to the sick person's life-world²⁵, thus hindering their ability to make decisions and plan for the future. A 32-year-old woman diagnosed with a severe intestinal neuropathy, whose life depends on being connected to a feeding machine 14 hours a day, every day, explained her feelings of uncertainty before being diagnosed:

You live in an uncertain world; they don't know what's happening to you, nobody can answer your questions, because they really don't have an answer. You feel worse and worse, because nobody gives you the treatment you need. You just give up the life you had and turn to the desperate monotony of going from one doctor to another.

After being diagnosed, she acknowledges still feeling uncertain about her future mainly as a result of fears about the course of the illness and its constraints, but she recognizes the importance of 'having a name' to restore lost credibility:

When you eventually receive the expected diagnosis, no matter how bad or despairing it is, you feel as if a heavy weight has been lifted. Finally you can name it! For a while you feel like a 'normal person' again, because, despite having a rare disease, you can show everybody that you are not that *imaginary sick* they thought you were (emphasis added).

²⁴ Or at least to be recognized as sick, a 'legitimation for a medical sick role' (KLEINMAN, 1980)

²⁵ In the sense of *lebenswelt* (HUSSERL, 1991).

Political invisibility: permission to be ill and the right to be cared for

Medical and social invisibility is inextricably linked to politics. Political invisibility occurs when there is no visible social or public health problem, and the state therefore overlooks the care needs of those affected. Some invisible illnesses are not adequately reflected in the official statistics, or in health policies and programmes, undermining citizens' rights and equal access to health care services and social services or benefits (AVELLANEDA *et alii*, 2007; DUMIT, 2006)²⁶. 'New illnesses', illness processes with no diagnosis and rare diseases, in other words, all those not common and less prevalent illnesses may fall into this category. Some health associations are campaigning for rights to be recognized, for an adequate health care for sufferers, and to make these illnesses socially visible. Their presence and voice are not yet the focus of a political agenda, and sometimes may be misunderstood as 'politically incorrect'²⁷. The needed care, visibility and rights are still a long way from being provided for, as the young woman suffering from a rare disease clearly expresses in a public letter on the web:

We feel alone and neglected by our country's health system. WE EXIST and we also have the right that they investigate about our pains to find effective treatments, that will one day allow us to enjoy our missing lives again (emphasis on the original).

Care rights are constructed both socially and medically. When illnesses, sufferings and unwellnesses are not recognized socially and/or medically, the care needs of the sick are politically

²⁶ "We don't even have a code for this disease, so we're not going to pay you" (JOHNSON, 1996) quoted in DUMIT (2006:577) to show an institutional form of exclusion – if there is no code, there is no care (2006:587) - of some sufferings or what the author call 'contested illnesses'.

²⁷ Some of these patients associations and sick persons define themselves as having a 'politically incorrect illness', for example, a recent publication with an explicit title: VALVERDE, Clara (2009) *Pues tienes buena cara. Síndrome de la Fatiga Crónica. Una enfermedad políticamente incorrecta. [But you look good. Chronic Fatigue Syndrome. A politically incorrect illness]*

neglected or overlooked. Health and social services and their supply-demand relationship are politically constructed on priorities that respond to political, economic and socio-cultural rationalities. When demands do not fit with the market logic, some people's needs and rights can be sidelined²⁸. Rare diseases are a paradigmatic example of this. Their low prevalence makes them invisible to most of society, which is unaware of their existence; they seem to be 'problems that affect only a few others'. They are not given sufficient political consideration because they do not fit comfortably into the logic of market system. Research and resources are paralyzed because they are neither statistically viable nor economically profitable. As a result, in a welfare state with public health and social services such as Spain, universality and equality can not always be guaranteed.

*The healthy-sick bodies paradox:
final considerations for future studies*

Sick people *inside* apparently healthy bodies? or Healthy people *inside* invisible sick bodies? I started by addressing the question of what an invisible illness is. In light of the discussion in this paper, a further question emerges: What does it mean to be ill? In other, words, how do sufferers of chronic illness perceive their invisible/visible chronic condition: do they feel sick? Are they sick? Do they look sick? Are they physically, socially, medically or politically recognized as sick? How do they see themselves, how do they want to be recognized and how do others see them?

Social and self-identity are grounded in social interaction, in the (re)presentation of the self through bodily performance in everyday life (GOFFMAN, 1979), whether or not this performance is illness or wellness (even a pretence of wellness). Two main options are open to those suffering from either a biomedically diagnosed chronic illness or a non-diagnosed chronic condition

²⁸ The economic interests of politicians, large medical corporations and the pharmaceutical industry play a major role in the supply-demand process, and subsequently, in the care services provided or offered.

or unwellness that is not visible to others: 1) to recognize, disclose and inform about it, and therefore make it visible, or 2) to hide it, and therefore remain invisible. These two individual choices have, as argued above, their pros and cons, and their consequences essentially stem from the social and medical response they receive. Neither option is free from the illness experience of moral suffering and this is especially relevant in chronic illnesses, because of the time factor involved. Chronicity plays an important role in how sick people deal with the issue of visibility. Hiding something for a few weeks or months is far easier than hiding it for years. The course of the illness can also add increasing constraints to the sick person's life, frustrating their attempts to normalize their social life by hiding their condition, and in some cases making it impossible to achieve. As the illness progresses, complaints about one's suffering are less avoidable, and the need to be heard, understood and accepted can become a major factor in moral and social support.

Chronically ill people, however, find themselves in a double bind situation in which the implicit or explicit contradictory social rules block any positive outcome. They are forced by 'others' to legitimise/negotiate their position/status in order to be recognized. If they do not, they risk social rejection; if they do, they may still risk social rejection. Pretending to pretend, they are locked in a paradox; there is no escape, *No Exit*, like in Sartre's play (*Hui Clos*, 1944), which ends with the famous quote "Hell is other people". However, it is only through this 'hell of other people' that sick people can be recognized and restore their damaged reputation, social image or identity (GOFFMAN, 1995). Constant torment and moral suffering are also an invisible part of the picture. Bringing more empirical data to that 'big' philosophical issue through a phenomenological approach to the chronic illness experience is, besides one of my ongoing dissertation themes, a wider subject of interest on which medical anthropology is well positioned to shed light.

On another hand, it is necessary to bear in mind that some people with a medically diagnosed invisible chronic illness (generally with mild or moderate limitations) might not – or do not want to – perceive/define themselves either as sick or as chronically

ill. For this reason I introduced these final considerations with the question of what it means to be ill. This not-ill perception suggests that invisibility may not entail a problem for these people because they do not feel the need for recognition, they do not feel disconfirmed or delegitimated, and therefore they are not socially rejected... because they are not sick? Based on my research to date and from personal experience, this is not the case for most sufferers, but it is a revealing and inspiring finding that should be further explored through a phenomenological approach²⁹, because it is related to an underlying notion of 'normality' and to 'identity'. These two concepts should be studied in the relationships and interactions of sick and 'healthy' people, as well as their way of 'being in the world'.

In summary, the illness visibility depends not on one gaze or perception but on several: the individual, the socio-cultural, the medical and the political. Similarly, invisibility does not exclusively depend upon the illness itself, thus illnesses are not 'naturally invisible' but invisibilized by the sick person, by a specific culture or socio-historical moment, or by a hegemonic biomedical model working in harmony with a political model that follows its own particular economic rationality. For these reasons, this approach to the visibility-invisibility problem of chronic illness and its consequences suggests the need for further medical anthropology research and analysis to contribute to the literature and knowledge of the chronic illness experience. Both experience-near and experience-distance perspectives and the analysis of the socio-cultural, medical, economic and political processes involved will advance our understanding of how and why some sufferings, unwellnesses and illness continue to be invisible.

Acknowledgements

I am grateful to the participants of the 6th Medical Anthropology at Home conference held in Royaumont, France (2010), particularly

²⁹ Following MERLEAU-PONTY'S (1993) *embodiment* analysis.

Haris Agic and Anita Hardon, and to an anonymous reviewer for their constructive comments on an earlier draft of this chapter. I would also like to thank my PhD thesis advisors, Josep M. Comelles and Susan DiGiacomo, for their careful reading of the manuscript and suggestions for improving it.

References cited

- ASBRING, Pia and NÄRVANEN, Anna-Liisa (2004) "Patient Power and Control: A Study of Women With Uncertain Illness Trajectories", *Qualitative Health Research* 14 (2): 226-240.
- AVELLANEDA, Alfredo; IZQUIERDO, Maravillas; TORRENT-FARNELL, Josep and RAMÓN, José R. (2007) "Enfermedades raras: enfermedades crónicas que requieren un nuevo enfoque sociosanitario" [Rare Diseases: chronic diseases that need a new approach], *Anales Sistema Sanitario Navarra* 30 (2): 177-190.
- BECKER, Howard (1964) *Los extraños. Sociología de la desviación* [*Outsiders. Studies in the Sociology of deviance*]. Buenos Aires: Tiempo Contemporáneo.
- CHARMAZ, Kathy (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.
- COMELLES, Josep M. and MARTÍNEZ-HERNÁEZ, Àngel (1993) (eds.) *Enfermedad, cultura y sociedad* [Illness, culture and society]. Madrid: Eudema.
- COMELLES, Josep M. and PERDIGUERO, Enrique (2000) (eds.) *Medicina y Cultura. Estudios entre la Antropología y la Medicina* [Medicine and culture. Essays in the borderland between anthropology and medicine]. Barcelona: Bellaterra.
- DIGIACOMO, Susan (1992) "Metaphor as Illness: Postmodern Dilemmas in the Representation of Body, Mind and Disorder". *Medical Anthropology*, 14: 109-137
- DUMIT, Joseph (2006) "Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses", *Social Science and Medicine*, 62: 577-590.

- GOOD, Byron J. (1977) "The heart of what's the matter: the semantic of illness in Iran". *Culture, Medicine and Psychiatry*, 3: 381-418.
- GOOD, Byron J. and DELVECHIO GOOD, Mary-Jo (1982) "Towards a Meaning-Centered Analysis of Popular Illness Categories: 'Fright Illness' and 'Heart Distress' in Iran", In Marsella, Anthony J. and White, Geoffrey M. (eds.) *Cultural Conceptions of Mental Health and Therapy*, Dordrecht: D. Reidel.
- GOOD, Byron (2003) *Medicina, racionalidad y experiencia. Una perspectiva antropológica. [Medicine, rationality and experience. An Anthropological Perspective]* Barcelona: Bellaterra.
- GOFFMAN, Erving (1979) *Relaciones en público. Microestudios del orden público. [Relation in public. Microstudies of the Public Order]* Madrid: Alianza Editorial.
- GOFFMAN, Erving (1995). *Estigma. La identidad deteriorada [Stigma. Notes on the Management of Spoiled Identity]*. Buenos Aires: Amorrortu.
- HAY, M. Cameron (2010) "Suffering in a productive world: Chronic illness, visibility, and the space beyond agency", *American Ethnologist* 37 (2): 259-274.
- HUSSERL, Edmund (1991). *La crisis de las ciencias europeas y la fenomenología trascendental. Una introducción a la filosofía fenomenológica [The crisis of the European sciences and transcendental phenomenology. An introduction to phenomenological philosophy]*. Barcelona: Editorial Crítica.
- JOACHIN, Gloria and ACORN, Sonia (2000) "Stigma of visible and invisible chronic conditions", *Journal of Advanced Nursing* 32 (1): 243-248.
- JOHANSSON, Eva E.; HAMBERG, Katarina; WESTMAN, Göran and LINDGREN, Gerd (1999) "The meanings of pain: an exploration of women's descriptions of symptoms", *Social Science & Medicine*, 48: 1791-1802.
- JOHNSON, Hillary (1996) *Osler's web: Inside the labyrinth of the chronic fatigue syndrome epidemic*. New York: Crown Publishers.
- KLEINMAN, Arthur (1980) *Patients and Healers in the Context of Culture*. Berkeley: University of California Press.

- KLEINMAN, Arthur (1988) *The illness narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- KLEINMAN, Arthur (1992) "Pain and resistance. The delegitimation and relegitimation of local worlds" in DELVECHIO GOOD, Mary-Jo. BRODWIN, Paul E.; GOOD, Byron J. and KLEINMAN, Arthur. *Pain as Human Experience: An Anthropological Perspective*. Berkeley: University of California Press.
- KLEINMAN, Arthur (1995) *Writing at the margin: discourse between anthropology and medicine*. Berkeley: University of California.
- KLEINMAN, Arthur and BENSON, Peter (2004) "La vida moral de los que sufren enfermedad y el fracaso existencial de la medicina" [The moral life of sufferers from an illness and the existential failure of medicine], *Humanitas Monográfico* 2: 17-26.
- MASANA, Lina (2008) *Cronicidad y Dependencia. Necesidades asistenciales en adultos con enfermedades crónicas y dependencia, y su red social de apoyo en el contexto de la reciente Ley de Dependencia*. Medical Anthropology Masters Degree final work (M.Sc.). Universitat Rovira i Virgili: Tarragona [not edited yet].
- MASANA, Caterina (2010) "Self-care and management of adults with chronic illness and dependency: The Spanish case in the context of the new Dependency Law", In FAINZANG, Sylvie, EINAR HEM, Hans and BECH RISOR, Mette (eds.) *The taste for knowledge. Medical anthropology facing medical realities*. Denmark: Aarhus University Press.
- MERLEAU-PONTY, Maurice [1945] (1993). *Fenomenología de la percepción*. [Phenomenology of Perception.] Barcelona: Planeta.
- MILES, Anne; CURRAN, Valerie; PEARCE, Steve and ALLAN, Lindsey (2005) "Managing constraint: the experience of people with chronic pain", *Social Science and Medicine* 61: 431-441.
- NETTLETON, Sarah; O'MALLEY, Lisa; WATT, Ian and DUFFEY, Philip (2004) "Enigmatic illness: narratives of patients who live with medical unexplained symptoms", *Social Theory and Health* 2 (1): 44-66.
- NETTLETON, Sarah (2005) "I just want permission to be ill': Towards a sociology of medically unexplained symptoms", *Social Science and Medicine* 62 (5): 1167-1178.

- PARSONS, Talcott (1999). *El sistema social [The social system]*. Madrid: Alianza Editorial.
- PERDIGUERO, Enrique (2004) "El fenómeno del pluralismo asistencial: una realidad por investigar" [The phenomenon of healthcare pluralism: a reality to be researched], *Gaceta Sanitaria* 18 (Supl 1): 140-145.
- SCHEPER-HUGHES, Nancy and LOCK, Margaret M. (1987) "The Mindful Body: A prolegomenon to Future Work in Medical Anthropology", *Medical Anthropology Quarterly*, New Series, 1 (1): 6-41.
- VALVERDE, Clara (2009) *Pues tienes buena cara. Síndrome de la Fatiga Crónica. Una enfermedad políticamente incorrecta. [But you look good. Chronic Fatigue Syndrome. A politically incorrect illness]* Madrid: Ediciones Martínez Roca
- WARE, Norma C. (1992) "Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome", *Medical Anthropology Quarterly*, New Series, 6 (4): 347-361.
- WARE, Norma C. and KLEINMAN, Arthur (1992) "Culture and Somatic Experience: The Social Course if Illness in Neurasthenia and Chronic Fatigue Syndrome", *Psychosomatic Medicine* 54: 546-560.
- WARE, Norma C. (1993) "Society, Mind and Body in Chronic Fatigue Syndrome: An Anthropological View" Ciba Foundation Symposium; 173: 62-73; discussion 73-82.

THE RISK OF VENOUS THROMBOSIS AND ITS TRANSMISSION: MEDICAL PROGRESS AND LOSS OF BODY IMAGE

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Advances in epidemiological research have led to the notion of a person at risk of developing disease. This notion of ‘person at risk’ has taken on new dimensions with the development of molecular medicine and the hope of establishing relationships between genetic mutations and illnesses, opening the way to predictive medicine. However, this simplistic deterministic view of genetic research is not so easily applied (BOURRET, 2007) and the development of epigenetic research, as in the case of Alzheimer’s disease (LOCK 2005) has put a damper on the initial enthusiasm.

The case of multi-factor illness is even more complex. Looking at venous thromboembolism disease, a category that encompasses the illnesses known to the lay public as embolism and phlebitis, mutations have been discovered in genes coding for two coagulation factors (F V Leiden and 2021A prothrombin). But as hopes of deciphering all the genetic codes governing this complex disease recede, complex clinical reasoning has emerged which has turned out to be more discerning (COUTURAUD *et alii*, 2006, 2009: FIT study). From the scientific viewpoint, attempting to reduce risk leads to more complexity. For the public at large, these advances “may actually lead to the generation of further uncertainty, or the accentuation of existing uncertainty” (STEFFE, JENKINS and JESSEN 2005). Fifty years of popularization of genetic determinism have left their mark on the public and a return to an earlier model leaves families facing a risk that is hard to understand without the existence of a gene reified as a causal factor.

How can a family grasp the risk that is announced after a family member has suffered an episode of thromboembolism, when genetic tests have proved to be negative? ¹

For medical personnel, information must be communicated when preventive measures can be envisioned, and counseling is an ethical obligation. We know that this information on risk can be meaningful or effective only when it is given in the framework of patient education.² Patient education must be centered around the learners, their previous knowledge and apprehension of risk, factors that vary with their lifestyle and the structure of the community to which they belong (DOUGLAS and WIDLAVSKY, 1982). To prepare these educational measures the medical staff called in an anthropologist (HAXAIRE, *to be published*).

In this work on the body we will focus on the previous knowledge through which patients and their families interpret the information they receive on the risk of thromboembolism. We will not pursue the question of transmission in the familial configuration, covered in another publication, nor the question of different kinds of treatment and their impact on risk recognition.

As far as we know, in the case of thromboembolism most research on risk perception has studied the psychological distress induced by the announcement of the results of genetic testing and its relationship to risk perception. These studies have been done by health psychologists (KORLAAR *et alii*, 2005), who had previously worked on quality of life (KOORLAR *et alii*, 2004), testing predictive models of risk apprehension, for instance the common sense model (KAPTEIN *et alii*, 2007). Our approach is different, developing a path opened by anthropologists.

As S. GIFFORD (1986) rightly points out “one cannot assume that epidemiological and clinical notions of risk can be easily

¹ The models of transmission highlighted for genetic disease become irrelevant (HENDERSON *et alii*, 2000; PONDER *et alii*, 1996), and families refer to models that are more deeply rooted in the lay imagination of the body to manage the uncertainty that stems from the diagnosis.

² DECCACHE A., LEVENDHOMME E., 1989, 2004.

translated into lay notions of risk". Gifford worked with women at risk for breast cancer and found that they turned this unknown risk factor into "a perception of ill-health", a sort of intermediate state of illness, thereby 'objectifying' the risk. The disease discussed in this paper is even more difficult to comprehend for the public than cancer. This disease is due to the formation of a clot in a vein. This is not usually visible and the persons at risk do not show any signs which are easily recognizable. Lay people are aware of the fact that it can manifest itself in two distinct ways: namely "embolism" and "phlebitis". But it is a pathology which features a wide range of diverse symptoms. Faced with the uncertainty engendered by this hazard and the complexity of linking together the two clinical manifestations of the disease – namely deep vein thrombosis and pulmonary embolism – family members of the *propositus* develop their own construction of signs and symptoms, linked to imaginary forms of the material body. They attempt to confront the uncertainty and distress caused by the disruption of their lives when the risk is announced, creating an illusion with known factors. As G. BECKER wrote in 1997 (cited by SVENDSEN, 2005), "continuity is an illusion. Disruption to life is a constant in human experience. The only continuity that has staying power is the continuity of the body, and even that is vulnerable. But that reality is too unsettling for people to live with. Faith in continuity of the body may preserve the illusion of a more sweeping continuity".³

The body discussed here is not the body that the biomedical corps has taken as the basis for the semiology of thromboembolism. As shown by the anthropology of health (let us remember A. YOUNG, 1981), lay interpretation of symptoms refers to a body that is deeply rooted in a specific imaginary representation. Anthropologists in France have described the cultural framework of this representation (DURIF-BRUCKER, 1994, among others). Thus anthropologists 'at home' must make use of their familiarity with the foundations of the discipline as well as with the historical

³ Cf *illusio* (BOURDIEUX, 1997).

and ethnographical context to analyze the highly contemporary nature of these health issues.

*Venous thromboembolism, risk factors and clinical diagnosis:
patients faced with medical breakthroughs*

ADVANCES IN THE UNDERSTANDING OF IDIOPATHIC VENOUS
THROMBOEMBOLISM: THE FIT STUDY

Lay people are more aware of arterial risk, such as cardiovascular infarction or stroke, than of VTE risk. Recent studies suggest a high incidence of VTE with increased age, with one episode per hundred people over 75 years old. Besides the immediate risk of death, another concern is the high recurrence rate, especially when the first episode occurs in the absence of recognized risk factors (surgery, pregnancy or childbirth, bed rest, etc.), called 'idiopathic'. These data suggest that VTE is a major public health issue.

About one-quarter of patients who develop VTE, have 'unprovoked VTE'. One-third of such patients have identifiable genetic predispositions to thrombosis (mainly factor V Leiden and the G20210A prothrombin gene). But what about the other two-thirds?

VTE is a complex disease involving many known and unknown risk factors. Knowledge on the coagulation process involved is not stabilized: many coagulation factors have been described and research on genetic background is ongoing. The initial enthusiasm following the discovery of a genetic background in the 90's, especially the factor V mutation, is now counterbalanced by the more complex hypothesis of so-called 'idiopathic VTE'. Indeed, researchers feel that they have discovered only the visible part of the iceberg, and put forward the importance of the clinical presentation of VTE as idiopathic.⁴ This also means that VTE is a multi-factor disease. The underlying hypothesis of the FIT study

⁴ Another key element of this medical reasoning is the statistical issue, with the knowledge of a 9 % annual recurrence rate of VTE for a first episode

(COUTURAUD *op. cit.*) was based on potential inherited conditions shared by close family members, whether these conditions had already been identified (genetic variation of the factor V Leiden or prothrombin mutation) or not. Interestingly, the hypothesis explored by clinical researchers is far more complex than a straightforward explanation of a “one risk factor-one disease theory”. Patients and family members may have the opportunity to appraise such complexity or not.

Our hypothesis is that these advances in medical knowledge may be a source of bewilderment and dismay for patients and their families, because they make the risk more abstract and difficult to comprehend. Patients and their families may not easily grasp this subtle clinical reasoning and are thus inclined to deny the risk. Or, as mentioned above, they develop their own construction of symptoms and risks.

FAMILY SAMPLING: COMPOSITION AND EXAMPLES

We have studied the way lay people apprehend this potential risk of VTE. For this purpose we focused on families of patients who had suffered a first episode of so-called ‘idiopathic VTE’, drawn from among the volunteers already included in the FIT study. They had already filled out informed consent forms. These forms explained the VTE process to patient and family members. Briefly, they were told that clots occurring mainly in lower limb veins (phlebitis or deep vein thrombosis - DVT) can potentially migrate to the pulmonary arterial circulation system (pulmonary embolism - PE). Information was given about VTE risk factors, including knowledge on high-risk circumstances (surgery, among others) and on inherited conditions (factor V Leiden etc.). As a consequence, both patients and family members had been provided with the results of genetic testing performed on blood samples. In this context, patients and families received oral and written recommendations, such as the potential usefulness of

of ‘idiopathic’ VTE (versus a 2% rate in the case of a “provoked” VTE following surgery).

preventive anticoagulation medication under risk circumstances (surgery) and the benefits of elastic compression stockings.

Our sample consisted of ten families, each including the patients and their first-degree relatives.

These subjects were recruited between September 2008 and March 2009 by GETBO research assistants. For 10 families (12 were contacted) 37 out of 49 individuals were available. They were divided into groups according to the manifestation of thromboembolism in the *propositus* – embolism or phlebitis. Half were carriers of the genetic mutation identified.

The accounts of the *propositus*' illness given by the *propositus* and by each family member were taken down by the anthropologist, either in a separate office at the hospital, or at the homes of those who could not or would not come to the hospital (37 interviews and family diagrams). It was clearly stated that the research was aimed at preparing educational measures for prevention purposes. The families who had themselves suffered concurred with this goal. It should be remembered that they had already volunteered under the FIT protocol. Interviews were conducted in two phases. First the subjects gave their account of the illness episode, with queries on the context, the understanding of the process and the subject's reaction to the care and treatment given. Secondly the subjects were asked to diagram their family on a paper board, and were asked for commentary on the proximity between the *propositus* and the family members represented, and their experience of the episode.

These accounts allowed us to see the relationships established between disease etiology, symptoms, contexts and relevant care.

We will now take examples drawn from this broad corpus. In our view it is interesting to develop the cases of two very different families.

- in the first family [26] (10 members, 8 interviews), the patient, a 56-year-old woman, current smoker, was hospitalized for an episode of PE (embolism) following DVT (phlebitis); both her mother and one brother among nine children had suffered previously from episodes of DVT and no genetic mutation has been detected;

- in the second family, [27] (4 members, 4 interviews) the patient, a 18-year-old woman, suffered from an idiopathic DVT (phlebitis) and the father has a past history of DVT; presence of the factor V Leiden mutation was detected in the patient, her mother and sister, but not in her father.

From the systemic perspective, our two families differ:

- the first family [26] (no genetic mutation) consists of nine children loosely connected together; communication is scarce, if any: “each for himself”.
- the second family has fewer but more connected members; the lack of a systematic link between the presence of the genetic mutation and the occurrence of VTE is a source of perplexity: “my daughter has the gene and I have the phlebitis” (father).

But these contrasts do not appear as relevant for our topic here, as the difficulties encountered by patients and family members in appraising the risk of VTE are to be put in perspective with the need to link VTE occurrence with a known sign or symptom.

PATIENTS AND FAMILY MEMBERS UNDERScore A BROAD LACK OF PRECISE
SIGNS OR SYMPTOMS, THE DIFFICULTY OF ASSESSING RISK IN AN EMERGENCY
SITUATION, AND A DISEASE EXPERIENCED AS TWO DISTINCT ILLNESSES

Indeed, the difficulty of appraising the risk, for the patient or for his family, is increased by the fact that a given episode of VTE does not systematically resemble another one, or at least, does not involve the same location. Having experienced a VTE episode itself does not ensure sufficient knowledge.⁵ As an example, one does not systematically find the given signs or symptoms in one's children. A mother, “who experienced a PE”, expressed her guilt at not having being able to detect early symptoms of PE in her daughter [152-1]: “she stayed with us and used to experience back

⁵“symptoms, I am not aware of any”... “I can't explain how this occurs”... “one knows about the danger of a clot that may go up to the heart” [26-1] says a man who suffered from an episode of DVT.

pain at times, so I did not bother; then, I have a past history of PE and I might have been aware then, when she started being short of breath; I sought doctor's advice for her; /the doctor was aware of my past history of PE and linked it to my mother's trouble: she was admitted immediately to the emergency ward." For others [27] "when you get a swollen leg, you immediately think of it" [DVT or PE? 77]. A woman from the first family [26] entered the hospital for an episode of PE following previous episodes of DVT; she linked these episodes to her mother's past history of DVT. But the woman's brother, also treated for a past history of DVT, says: "I am not aware of phlebitis symptoms, not at all, it's true that if we were aware, may be that would help. If we were told about a calf pain, like me, maybe we would seek for assistance, maybe..." [26-1 brother].

In such circumstances of a potentially life-threatening episode, a strong willingness to rely on the health care system is put forward: "what else is there to do if the physician does a good job?" [26-1]. Potential belief of self-helplessness is strengthened by the fact that the whole story of the emergency process (diagnosis and treatment of VTE) is usually explained to family members after recovery from the patient's acute episode. The perception of a potentially fatal, although avoided, issue is delayed: "hospital stay was very short... I did not realize" [26-2 son] says the son from the first family. This can minimize the episode's severity, as for the young sister of the 18-year-old patient from the second family [27], who compared with her own hospital stays: "well, she went to hospital and came back, she was put on injections... well I have been several times to hospital (fractures and plaster casts) since I was young, so..." [27-S-sister]. This was not previously the case.⁶

⁶ Past history of mothers and grandmothers is deeply rooted in the family knowledge: "I am aware of mum's phlebitis, I was told many times, I am 57 and I was told many times" [151]. "That was a real mess because you had to be bed ridden, immobilized to avoid that "its reach the heart, danger was there" [151] and hospital stay were prolonged with a recovery period that altered the whole family life.

Although phlebitis and pulmonary embolism are seen by clinicians as two aspects of the same disease (VTE), this is not clear to patients, even after experience of a VTE episode.

Pathophysiology is not systematically integrated in body image representation shared by lay people: in the case of VTE, adequate knowledge of the circulatory system, formalized in Europe only in the 17th century, is mandatory. For some patients and family members, circulation is viewed as a whole process and distinguishing between arterial and venous systems implies a strong effort to recall knowledge acquired in high school. As a consequence, interviews detected that past history of arterial hypertension was seen as a risk factor of VTE [119-P].⁷ Lung injury, coughing and shortness of breath are mysteriously linked with venous circulation, as well as are pulmonary arteries. Although migration of a clot from a distal vein to the heart seems plausible to patients and family members, the process involving right heart cavities and pulmonary artery circulation (and the resulting risk of death) appears as difficult to appraise – interviews retrieved the expression of “a clot, up to the heart”. The explanation of a possible lung injury is linked to health effects of smoking. This is consistent with the daughter [26] of the smoker patient from the first family who saw no connection between her mother’s PE episode and other family members’ DVT episodes: “no, it is not the same thing” [26-daughter]. Similarly, the patient’s brother, knew nothing of any history of PE in the family, saying: “I am not aware of any body who died from phlebitis” [26-brother].⁸

Even more challenging is the appraisal of a potential inherited risk of VTE: this is understandable if a mutation in the coagulation pathway is detected and known to patients and family members, but the risk may become ‘abstract’ for lay people faced with an idiopathic VTE episode – whether linked to a known genetic mutation or not – and its higher recurrence rate.

⁷ Some felt that prevention could help, as with regular check-ups for their work [19-2].

⁸ In the second family, [27] the father seems to suddenly acknowledge that: “then it can also go to the lung, as I was told.”

*From the lay point of view: towards mental representation
of what is unconceivable and the search for symptoms*

During interviews, patients and family members are obliged to talk about the illness, even if only to express denial.

Two different points of view emerged:

- first, the case of family members judged as ‘at risk’ tried to apprehend this risk of VTE through characteristics of the patient or of other family members with a past history of VTE;
- secondly, the case of patients of family members who had already experienced a VTE episode and who focused on the acute and/or chronic symptoms they had experienced – as the episode body memory.

FROM THE FAMILY PERSPECTIVE

Interviews conducted with family members detect only concerns about DVT risk: no link between DVT and PE is mentioned, while associations with varicose veins and/or other post-phlebitis sign/symptom – “circulation problems, heavy legs” are frequent.

Mention of the lower limb venous system evokes varicose veins or ulcers for instance [19], or [26] “she suffered... I was young... I know she underwent varicose veins sclerosis”, says the daughter from our first family [26]. Her uncle, the patient’s brother, informed us about the frequency of varicose veins, depicted as “knots”, surgery within this family (himself, parents and 2 or 3 sisters); he reinforced this concept by the doctor’s suspicion of a DVT seeing the patient’s legs “swollen and reddish”, as past history of varicose veins was present. This link between DVT and varicose veins is frequently reported “I don’t know how I got this phlebitis, I don’t know at all, may be vein fragility?” [151-2]. In the search for an explanation, fragility of the veins appears as plausible. This link appears to belong to our shared representations; for one subject the venous ulcers correspond to “something inside that needs to come out” (DURIF-BRUCKERT, *op.cit.*). They are indeed a manifestation of “bad” blood.

In the first family [26], the patient had sought medical advice following leg symptoms “a reddish leg, no pain, the whole calf red” that resembled symptoms experienced by his brother and mother. However, she didn’t make any connection with concurrent symptoms of chest pain. A particular pattern in this family is the lack of concern as regards PE risk/occurrence: “as embolism never occurs in the family” says this same brother, occulting the patient’s PE episode.

Our two families, selected among others, highlight two VTE risk factors: being overweight and “having a sedentary nature”. In the first family of nine brothers and sisters [26], who live near the parent’s home, loose relationship seems the rule. The patient, one sister, is depicted by all the other members of the family as “different” from a physical point of view – “overweight” – underscored by all: “when you look at her she is so hefty”... she is so inactive... Me, when I look at all the sports I am involved in! She is so inactive⁹... at least take a walk... Some times at the phone... I have a nap... she ought to loose some weight” says her own daughter. This daughter has no idea of a past history of DVT in her family and, as a person who practices sports, does not bother with this risk. Similarly, her son and brothers and sisters expressed the same belief, because they are involved in physical activities.

The patient from our second family is also depicted as “a hefty person” [27]. Members of this family appears to be deeply connected together, reinforced in that status by the knowledge of “the gene mutation”. The clinical suspicion of DVT was raised readily... “well, I was aware of that, as my grandmother had phlebitis, so my mother, we spoke of that in the family”, says the mother. According to her father, this 18-year-old patient is “overweight also, maybe that helps”, as was the grandmother: “my mother, I think she might have had phlebitis too... with such swollen legs... well we all are overweight”.

In other less specific surveys carried out in France concerning the body, the corporal heaviness that all the subjects underscore

⁹ Lack of exercise is indeed a risk factor for 50% of subjects in the Dutch survey (KOORLA, 2005).

is a sign of “poor circulation” and “blood problems” identified as a source of clogging and fouling, of blood clots that cause both swollen veins and “brain commotion” (vasco-cerebral accidents).

The father from this second family puts forward dysmenorrheal symptoms of his daughter: “she paid a visit to an endocrinologist, for weight problems, maybe that helped... menstruations were infrequent, maybe that helps too”.¹⁰ The prescription of hormonal contraception a few months before the DVT episode was mentioned in that instance. However, the link between menstruation / elimination of “spoiled blood” / overweight (DELANOE, 2006) may appear more relevant here.

Another clue consists in “having poor legs”, like the grandmother of our second family “who experienced phlebitis, but apparently, that is not due to the gene, well, because my husband does not have the gene... otherwise he would have it”, says the mother, later speaking of “my own mother has very poor legs ...she wears elastic stockings and can’t stand underpants because the legs are too swollen”. That is also the case for the father’s sisters. However, the young patient does not share such symptoms: “the thing is... I never had leg pain... even when I get my phlebitis, I never have pain... I do not feel any leg symptoms”. For the mother, the two daughters “bruise” easily, a symptom also recalled by the young sister. Both mother and the two daughters “have the gene mutation”. Ashamed by the occurrence of VTE at such a young age in her daughter, the mother is however comforted by the genetic findings: “when we got the tests results, we said, ok that explains... that was reassuring... we now can prevent recurrence... and avoid it”. The father does not express such a straightforward explanation: “well I am concerned, but what can I do? Nobody knows”.

Knowledge of genetic status, understood only as the presence or absence of factor V Leiden mutation, raises an additional concern within the family that previously linked leg symptoms (varicose vein – edema, leg pain...) to suspicion of DVT: “well we

¹⁰ Taken as a “circulatory problem” VTE risk is often linked to “being overweight and loss of mobility”, with the consequence of an insufficiency in “blood circulation speed”.

thought it might come from my father's side, because his sisters had past history of phlebitis and leg problems; but apparently it comes from my mother's side who never experienced such problems. My grandmother did have a problem once", says the young patient from our second family [27-P].¹¹

In the absence of symptoms linked to blood circulation, any appraisal of VTE risk is difficult, whether the purpose is to deny this risk by seeking discrepancies with the patient's condition, or on the contrary to seek out from whom it might be inherited.

FROM THE PATIENT'S PERSPECTIVE: TRACES

Faced with the risk of VTE recurrence, patients make their own assumptions about identified risk factors, or favor the most prominent symptom experienced as an alarm signal.

Eczema is seen as a sign of poor circulation. If the young patient of our second family, described as "overweight" [P-27] by her family does not mention this risk factor, other young women acknowledge this status: "so, I am bothered, for sure... I am overweight – looking at her lower limbs – I have circulation problems... Besides, I have eczema I can't get rid of and it may be linked to circulation, I was told" [119-P]. For the latter, eczema is the consequence of poor circulation,¹² consistent with lay knowledge that links this dermatological illness to alteration of blood nature – "too rich or bad".¹³

For the subjects, recurrence of the initial symptoms is an alarm signal. The young patient from our second family depicts herself as "traumatized" by the VTE episode: "as soon as she sees her leg swollen, she says, ho mum I am afraid!" reports her mother [27-P]. She paid a visit to the emergency room as soon as she detected

¹¹ We do not develop the inheritance perspective here, the quest of "who does this come from?" As an example, "because my husband has the Factor V, so does my daughter, like C... but C has the factor V and the factor 2... In the family all the boys have the factor V and none of the girls" [77].

¹² She does not entirely believe this unsubstantiated statement ("I was told of"), but mentions having "a bad blood circulation".

¹³ Whose consequence is a poor blood supply to the nerves [DURIF-BRUCKER 1994, HAXAIRE, 1999].

the slightest alteration in her leg: “well, I experienced that two times or more... I had a really swollen leg but I did not get the phlebitis...”. And “initially, I had no calf... from the calf to knee it was the same stuff...” – laughing [27-P].

A feeling of discomfort is an alarm signal: “meanwhile afterwards, I felt bad when I walked, when walking fast, I felt bad, I had little cramps in my calves, then well...”. This alarm signal serves as a reminder to take exercise [27-P].¹⁴

Similarly, for her father, who “does not have the gene”, perplexity may reinforce the perception of symptoms: “when I feel my limb... sometimes it tickles a little... I need to have a walk”. This sign is a memory, linked to blood circulation: “Well, here I feel uncomfortable, tightened... it is jammed up in there, bad irrigation... that is not continuous... I can’t guess what’s happening” [27 father].

Sequels are equally symptoms: “now, who get sequels, that remains sequels of phlebitis, leg swollen, then, ...it’s as big as this...” [151]. No sequel of PE is mentioned by the patient from our first family [26]; this woman did not link chest pain to her past history of phlebitis. A woman in another family has the opposite attitude [77], carefully looking for “traces”. The mother says: “I got traces” and recognize similarities in her daughter “who has not recovered... who has 15 – 17% of her lung not recovering yet... so she gets sequels... 15 or 17% of the lung... fatigue or weight gain... she feels it”.¹⁵

Following her phlebitis the patient from the first family [26] stopped her contraception and underwent definitive surgery at the time of a complicated pregnancy. In this case VTE was closely linked to hormonal status; a similar link with menopause and its symptoms is likely to happen, since no relief of these symptoms is expected.¹⁶ This increase in symptoms at the time of menopause reinforces anxiety, as menopause and the absence of

¹⁴ “Ha, I am ok, I think that helps because usually, after sports, I have better feet, less swollen, I think that helps the blood flow.”

¹⁵ “She stopped anticoagulation one year... and when she is tired, she is out of breath, she needs her small inhaler.” [77]

¹⁶ Hormonal replacement therapy is counter-indicated.

menstrual periods may be perceived as a lack of elimination of blood impurities. Consequently, for those who have experienced an episode of VTE, sequels or traces recall the risk and, hopefully, contribute to better adherence to preventive measures.¹⁷

Conclusion

The difficulties that patients and family members have in comprehending the risk of VTE, and the distress following the announcement of the disease are the first findings to emerge from this study. Families express a wide range of opinions and feelings, from denial to reappraisal of the risk, depending on their own perception. Knowledge of inherited risk factors linked to the coagulation pathway is not discussed. From what was said during the interviews, knowledge of this particular disease, is a source of uncertainty and may increase distress. Thus, it is often passed over by patients and family members. They previously gave their informed consent to enter the FIT study and asked their family members to do likewise, and in that sense they faced the risk. However, knowledge of a particular genetic status generated further uncertainty. Integrating this new information as well as resuming continuity are helpful, both for the patient's life and for that of any other family member. We, like SVENDSEN (*op.cit.*), have encountered denial attitudes, for instance in the case of families in which varying genetic status introduced unacceptable differences between members.

We are aware of the influence of the familial, social, and political context on opinions and feelings (STEFFEN, JENKINS and JESSEN, 2005). But, we have focused here on the body. In any event, families opt for identification of the symptom, in the sense of a perceptible or visible phenomenon; this is linked with the imaginary vision of the material body. This is illustrated by the case of eczema, seen as an illness that is due to poor blood circulation. This does not exclude any moral background behind a particular sign, nor that

¹⁷ "Since then I put on my stockings, ha it's so big like that, I could not stand it without them, it's the first thing I put on in the morning." [151]

this sign is proposed among others for this reason, nor that this choice is favored by the group, in that particular group context of power or affective relationships. Stigmatizing the patient's obesity or lack of fitness is a way for family members to cope with the risk, if they themselves are personally active and involved in keep-fit activities. Control and uncertainty are always under negotiation within social relationships. Focusing on visible signs is a way of gaining confidence when faced with an intangible risk.

Whether adequate information has been provided or not, coping with uncertainty is the rule. The greater the uncertainty, the more families find help through reference to prior knowledge that is both deeply rooted in lay culture and continuously evolving.

Our study shows that not only are the biomedical symptoms variable, but also that the patients and their families in their uncertainty latch onto selected symptoms that make sense to them in their personal context. This work shows once again the need for a non-standardized approach in educational measures and for a cross-disciplinary approach.

References

- BECKER, Gay (1997) *Disrupted Lives: How people create meaning in a chaotic world*. Berkeley. University of California Press.
- BOURDIEU, Pierre (1997) *Méditations pascaliennes*. Seuil.
- BOURRET, Pascale et JULIAN-REYNIER, Claire (2007) "Prédiction des risques génétiques de cancer: complexités et incertitudes de la communication médicale", in Ilario ROSSI (ed.), *Prévoir et prédire la maladie. De la divination au pronostic*, Monts, Éditions Aux lieux d'être.
- COUTURAUD, Francis, KEARON, Clive, LEROYER, Christophe, MERCIER, Bernard, ABGRALL, Jean François, LE GAL, Grégoire *et alii* (2006) Incidence of venous thromboembolism in first-degree relatives of patients with venous thromboembolism who have factor V Leiden. *Thromb Haemost.* 96: 744-9.
- COUTURAUD, Francis, LEROYER, Christophe, JULIAN, Jim A., KAHN, Suzanne, R., GINSBERG, Jeffrey, S., WELLS, Philip, S., *et alii* (2009) "Factors that predict risk of thrombosis in relatives of

- patients with unprovoked venous thromboembolism". *Chest*. 136:1537-45.
- DECCACHE, Alain and LAVENDHOMME, Eric [1989] (2004) *Information et éducation du patient* Bruxelles: De Boeck.
- DELANOE, Daniel (2006) *Sexe, croyance et ménopause*. Paris. Hachette.
- DOUGLAS, Mary and WILDAVSKY, Aaron B. (1982) *Risk and Culture: An essay on the selection of technical and environmental dangers*. Berkeley. University of California Press.
- DURIF-BRUCKERT, Christine (1994) *Une fabuleuse machine, anthropologie des savoirs ordinaires sur les fonctions physiologiques*. Paris. Métailié.
- GIFFORD, Sandra (1986) "The meaning of lump: a case study of the ambiguity of risk" in Jane CRAIG R., STALL Ron and GIFFORD, Sandra (eds). *Anthropology and epidemiology: Interdisciplinary approaches to the Study of Health and Disease*. Dordrecht. Reidel.
- GOOD, Byron (1998) *Comment faire de l'anthropologie médicale*, Paris, Les Empêcheurs de Penser en Rond.
- HAXAIRE, Claudie, LEROYER, Christophe, COUTURAUD, Francis, à paraître, "Anthropology and Setting up Research on Therapeutic Education: Eclectic Methodology to Capture the Way Families with Risk of Thromboembolism Cope with Uncertainty", in GOOBERMAN-HILL, Rachel & TANTCHOU, Josiane C. convenors, n° spécial issu du workshop WO26, Applied anthropology, crisis and innovation in health and medicine, EASA congrès, Maynooth 2010, *Anthropology in Action*.
- HAXAIRE, Claudie, BRABANT, Juliette, WALD, Paul (1999) "Usages et compétences familiales en matière de psychotropes: comparaison entre zone rurale (bocage Ouest-Ornais et Nord Mayennais) et zones urbaines (Rouen et Antony-Fresnes). Paris. Rapport MIRE.
- HENDERSON, Bethan J. and MAGUIRE Bryan Y. (2000) Three lay mental models of disease inheritance, *Social Science and medicine* 50: 293-301.
- KAPTEIN, Ad A., van KORLAAR, Inez M., CAMERON, Linda D., VOSSEN, Carla Y., VAN DER MEER, Felix J. M., ROSENDAAL FRITS, R. (2007) "Using the common-sense model to predict risk perception

- and disease-related worry in individuals at increased risk for venous thrombosis”, *Health psychology*: official journal of the Division of Health Psychology, American Psychological Association 26(6): 807-12.
- KORLAAR van, Inez M., VOSSEN Carla Y., ROSENDAAL Frits R., BOVILL Edwin, CUSHMAN Mary, NAUD Shelly, KAPTEIN, Ad A. (2004) “The impact of venous thrombosis on quality of life”, *Thrombosis research* 114: 11-18.
- KORLAAR VAN, Inez M., VOSSEN Carla Y., ROSENDAAL FRITS R., BOVILL Edwin, G., NAUD Shelly, CAMERON Linda D. and KAPTEIN, Ad A., (2005) “Attitudes toward genetic testing for thrombophilia in asymptomatic members of large family with heritable protein C deficiency”, *Journal of Thrombosis and Haemostasis* 3 n° 11: 2437-2444.
- LOCK, Margaret (2005) “Eclipse of the gene and the return of divination” *Current Anthropology* 46, sup dec S47-S70.
- STEFFEN, Vibeke, JENKINS, Richard and JESSEN, Hanne (2005) *Managing uncertainty*. Copenhagen. Museum Tusculanum Press.
- SVENDSEN, Mette N. (2005) “Pursuing knowledge about a genetic risk of cancer” in STEFFEN, Vibeke, JENKINS, Richard and JESSEN, Hanne (2005) *Managing uncertainty*. Copenhagen. Museum Tusculanum Press. 93 -121.
- YOUNG, Allan (1981) “When rational man fall sick: an inquiry into some assumption made by medical anthropologist” *Culture, Medicine and Psychiatry* V: 317-335.

THE BEAST IN ME.
THE EVOLUTION OF MAD BODIES
IN CONTEMPORARY EUROPE¹

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The beast in me
Is caged by by frail and fragile bonds
Restless by day
And by night, rants and rages at the stars
God help, the beast in me
The beast in me
Has had to learn to live with pain
And how to shelter from the rain
And in the twining of any eye
Might have to be restrained
God help the beast in me.²

Christmas 2009. A multinational corporation launched an advertising campaign in Spain for a functional food – Danacol ® –, the effect of which was to decrease the cholesterol rate in blood. One of the commercials concluded: “Fight the *excesses* of Christmas. Take....” Another shows a dialogue between a husband and his wife:³

¹This paper comes from the debates of the project R & D *La emergencia de las sociedades obesogénicas o de la obesidad como problema social* (CSO2009-07683) financed by the Spanish MECI directed by per Mabel Gracia (URV). MY acknowledgement to Mabel Gracia Maria Antonia Montserrat, Julia Ledo, Mariola Bernal, Maria-Lluïsa Maldonado, Miguel Angel, Montserrat García, Louis Assier-Andrieu i Anne Gotman for their comments and suggestions. A part of the results are in Gracia *et alii* (2007) and Gracia & Comelles (2007).

²Nick LOWE (1994) “The beast in me” *The Impossible Bird*.

³ *Danacol® excusa numero 9*. http://www.youtube.com/watch?v=XyGPaXHYtgw&feature=Playlist&p=D1208AE414D463D5&playnext=1&playnext_from=PL&index=7 Visited 28.02.2010.

VOICE-OVER: What's your excuse for not reducing your cholesterol?

VOICE-OVER: Excuse number 9:

HUSBAND: I watch my cholesterol, eat well, and exercise. I used to say that, but it was an excuse, I was fooling myself. I exercised.

WIFE: But your cholesterol kept going up.

HUSBAND: I ate salads.

WIFE: But you never stopped overindulging with your friends.

HUSBAND: I learned that with each excess I went off my diet my cholesterol got worse and I had to reduce it.

VOICE-OVER: With cholesterol there can be no excuses. The excess of cholesterol can clog your arteries. Danacol reduces the amount of cholesterol your body absorbs by helping to remove it. Danacol lowers your cholesterol.

HUSBAND: Don't hide behind excuses. There aren't any warning signs for high cholesterol-Reduce it now.

The first commercial appeals to the individual consciousness after the Christmas meals excess, because in Iberian ethnoscares the family feasts are gastronomic.⁴ The second plays on two definitions of *excess*. One is something that can be measured in. The other, however, has a *cultural, qualitative* dimension. There are excesses for which *there are simply no excuses*.⁵

The *Enciclopedia Catalana* contains both of these meanings for *excess*. The *Diccionario de la Real Academia Española* adds *abuso, delito* and *crimen* (*abuse, offence* and *crime*), and the *Diccionario de Uso del Español* by María Moliner (2002: 1247) further extends its meaning with *dissolute* or *licentious* behaviour, and, in general, activity in public that may upset others. All three speak of going beyond certain limits but they put their definitions in order of importance and the first is always the measurable

⁴ The Holidays begin the 24th December by night, Christmas Day – in Catalonia also the 26th December, the 31st January, New Year and the Epiphany (January 6). Every Holiday is associated with meals, some specific: *turron, Tortell de Reis, neules*, etc...

⁵ I have looked for Danacol commercials at an international level in Youtube. The word excess appears only in the Spanish ones.

limits. The *Webster's* (1996), on the other hand, emphasizes the values:

1. The state of surpassing or going beyond limits; the being of a measure beyond sufficiency, necessity, or duty; that which exceeds what is usual or proper; immoderateness; superfluity; superabundance; extravagance; as, an excess of provisions or of light. 2. An undue indulgence of the appetite; transgression of proper moderation in natural gratifications; intemperance; dissipation.

In British Enlightenment, excess meant “more than enough; superfluity, exuberance, state of exceeding, intemperance, transgression of due limits”(JOHNSON & WALKER, 1828). However in Susan DiGiacomo’s translation of the commercials audio, she does not employ *excess* for *exceso*, and the word do not appear in the Italian, English, Portuguese and French advertisements of Danacol.

My interest in the concept of *excess* was first aroused by its common use in the letters begging the admission of lunatics at the Hospital de la Santa Creu in Barcelona in the 18th and 19th Centuries.⁶ One of them was the letter sent to the Hospital, in 1769 by the governor of the criminal jurisdiction of the Council of Urgel, state to the board of trustees about “the unfortunate state of Juan Rocamora, a good-for-nothing farmhand, whose gluttonous and excessive drinking of wine both day and night has driven him mad. I was obliged to have him imprisoned in order to control his food and his drinking of wine and thus calm and quieting him, and having done so, he was returned home in the belief that his madness had been remedied. But, having recovered his freedom, he once again fell to drinking wine in excess, spending the nights with his fellow gluttons, eating and drinking without measure. Some nights he woke his wife, and sent her to the barn to fetch a hen so that he might eat; and at the same time he sent her down to the cellar to bring him up a large flagon of wine so that he might put it on the fire to heat up. This madness of his has put his family in a state of constant fright and has resulted in his losing everything he has, which was but sufficient to live with the

⁶The hospital had an insane ward since 1401, see Comelles (2006).

decency of a farmhand.”⁷ *Excess*, then, in its application to human practices in 1769 and 2009, is the crossroads between science and morality, medicine, religion and values, between reason and madness, and between nature and culture.

On the notion of excess

Food, drink and lust soon became the focal point of the confrontation between the ancient Christian writers and paganism. These writers, however, never renounced the rationalism or the naturalism of medical writings (TEMKIN, 1991). Isidore of Seville (1993) made a synthesis and Aquinas (1955) accepted that a doctor is an *artifex factibus sanitatis* unaware of theological thought, a practitioner of health (GARCÍA BALLESTER, 1995). Scholastics assumed the naturalistic ideas of disease causality of the physicians.

The Hippocratic treatise *Peri diaites*⁸ states that man “cannot remain healthy on food alone; he must also take exercise. The effects are quite different but they complement one another as far as health is concerned. Exercise expends what has accumulated while food and drink restore what has been expended” (HIPPOCRATES 1986: 22). His main idea is that of an equilibrium that remains almost constant throughout life, of a *healthy diet* that is the result of a systematic observation of cases “when one is present and can observe a man changing in a gymnasium and carrying out his exercises, one can know him in such a way as to keep him healthy, depriving him of some things and completing his diet with others. If one is not present, it is impossible to prescribe food and exercise with any accuracy.” (HIPPOCRATES, 1986: 23). A healthy life must be contextualized so that one can “discern which exercises increase flesh and which decrease it, how exercise is related to the amount of food, the nature of individuals and age, and how it should be suited to the seasons of the year, the winds

⁷ AHSCSP *Manicomio Dementes* I. See about this case Comelles (2008).

⁸ See Hippocrates (1986), and the introduction by García Gual (1986). Before 1970, in Catalonia *règim* was the main word for *diet* in its nutritional meaning.

and the places people live and the constitution of the year. One should know when the sun rises and sets in order to be able to prevent the alterations and the excesses of food that cause human illness" (HIPPOCRATES, 1986: 23). And "if it were possible to find just the right proportion of food and exercise that were to offer no imbalance, to be neither *too much* nor *too little*, then the health of individuals could be accurately determined. But this is impossible." What is possible, however, is to make "a diagnosis that indicates what sort of imbalance will occur before an individual falls ill due to overindulgence. Because illnesses do not attack men without warning; rather, they incubate gradually and then reveal themselves suddenly" (HIPPOCRATES, 1986: 23). The term *diaites* has generally been translated as *regime of life* or *diet*. The most important of the Hippocrates approach to diet is his relativist perspective, and the idea of a conscious adoption of a way of life that has also effects on the *temperament*. With a correct *diaites*, without *excesses*, individuals can become "more intelligent and quick-witted than mere nature would allow" (HIPPOCRATES, 1986: 49).⁹ The concept of *diaites* also seems to have been taken up by the classical writers and by Christians (see MILLER, 1997, TEMKIN, 1991). The practice of asceticism in oriental monasticism (BROWN, 1993) and the *cardinal virtues* of man – justice, fortitude, temperance and prudence were inspired by Platón, Ciceró and Marcus Aurelius. Aquinas (1955) "derives the cardinal virtues both from their formal objects or the perceived kinds of rational good which they generally seek, and from the subjects, or faculties, in which they reside and which they perfect. In the sensitive appetites are temperance restraining pleasure, and fortitude urging on impulses of resistance to fear which would deter a person from strenuous action under difficulties. On the side of the formal object, which in all cases is rational good, we have the four variations. The order of objective reason as imposed on the appetite for pleasures demands the virtue of temperance; as imposed on the appetite, which is repelled by fear-inspiring tasks, it demands fortitude. Aquinas tried to give a systematic account

⁹ Kretschmer (1947) related body constitution with temperament.

of the group as far as it admitted of logical systematization. In so doing he naturally looked to the faculties employed and to the objects about which they were employed. He found it convenient to regard the action of reason, prudence, and the two passions of the sensitive appetite, lust and fear, as internal to the agent; while he regarded the action of the will as concerned with right order in regard to conduct. Thus with three virtues *ad intra* and one *ad extra* were established four cardinal virtues, contrary to Plato's scheme, in which all were directly *ad intra*, referring to the inner harmony of man."¹⁰

The continuity between *diaites* and the *temperance* and fortitude in Aquinas quotation, cannot conceal a difference that, in my opinion, is important. Hippocrates describes and occasionally advises; the scholar, Aquinas heritage, makes universal rules. Health in Hippocratic terms, is a condition of life that is locally adaptable and diverse, not a moral condition as Christianity believes.¹¹ He wants to show that rational principles – such as broad food choices and a variety of exercise types – can lead to the ideal of a healthy life. No mention is made of animality. Hippocrates interprets obesity or thinness in terms of measurable *excess* or *deficiency*, but always in a particular context. Theological virtue, on the other hand, imposes its embodiment (*ad intram*) to balance bodies and souls. The fact that Hippocratic relativism was clarified by scholasticism explains why the concept of *excess* went into moral decline: it was tied to the sin of gluttony, which, in the 18th century was extended to the consumption of spirits, particularly during the Reform. Excess was also linked to violence, lack of moderation, to the beast associated to the flesh. According to the Church, it is a cardinal sin: “As God hath planted in every man a natural desire of life, so the first and most immediate end of eating and drinking is for the preservation of it. But then we are always to remember, that it is life we are to provide for, and not

¹⁰ *Catholic Encyclopedia* (2009).

<http://www.newadvent.org/cathen/03343a.htm>. Visited February, 18, 2010.

¹¹ Cristianisme has very few food. Rubies, Joan-Pau (2007) show the adaptation of the monks to the material and cultural life in the Far East.

luxury; that the using God's creatures more liberally than nature requires or can bear, is not the way to preserve, but to shorten and destroy life" (Bishop GIBSON, in ATTERBURY *et alii* 1795).

Regulatory radicalism can also be seen in the prescribing of *diaites*. "Prescribing a regimen must be your main preoccupation: although you may not always give medicines, you will always prescribe a regimen" (GRASSET, 1883: 7) and "Regulate the times, the nature, the quantity and the number of meals; drinks; the times remedies are to be administered; and indicate whether the patient must be woken so that medicines can be administered. If he is bedridden, say whether he can be changed, his bed made, at what time, the type of bed and when the room needs to be cleaned. Say whether he can get up, go out" (GRASSET, 1883: 9). The Christian churches and medicine both obviously gave rise to laws but medicine made the effort to conceal its moral dimensions by using positivist language. This explains why the concept of *excess* can be used with such enormous ambiguity during the 21st century. The *Danacol* commercials are closer to the scholastic notion of virtue than the Hippocratic one, and biomedical discourse might be more "scholastic" in a theological sense than in an "experimental" one.

Excesses, animality and madness

The governor who sent Rocamora to the Hospital did not take doctors into account. The diagnosis of lunacy was made by the local community who had no alternative but to send him to the Hospital not for *care* but for a *cure*. Three months later he was discharged and the hospital board wrote that they had carried out "all the tests required by the Art of Medicine but neither the physicians nor the administrators could perceive the slightest indication of madness or believed that wine could turn him mad. The fault will not be cured by the Hospital: only abstinence or moderation in wine shall leave him free of its effects. All we have seen here is that he tends to speak more than is normal. The Administration can no longer tolerate his presence among the

insane because the purpose of this institution is to provide mercy not punishment.¹²

The Board, two canon priests and two members of the city council confirm that both they and the physicians examined Rocamora. In their letter they rebuke the governor and Rocamora's fellow citizens: it is they who have failed and Rocamora deserves no punishment. The response speaks of prudence and justice, and shows the relativism with which human behaviour could be viewed at the end of the 18th century in a Roman Catholic context.

Half a century later, Miquel May "did excesses that have obliged the Mayor to put a stop to the insults that he continually hurled at the authorities and other individuals. On 7 March he insulted the Priest and the Mayor in their homes, screaming death threats. A knife was taken off him and he was taken to prison. From there he was taken to the lunatic asylum, for certain symptoms of madness had been observed, but he was soon released because *such symptoms had not been evident during his detainment*". However, "having returned to his normal life he carried on as before insulting and threatening the Mayor. He was found to be in possession of a bradawl, of which he was relieved and taken to prison. Once released, he distributed leaflets in the streets of Vich insulting the vicar-general, the schoolmaster and the priest of Taradell.

As well as this, there was the much-talked-about and notorious incident in which he contradicted the Preacher in the Cathedral of Vich before an enormous crowd of people and which prompted the authorities to take him to the lunatic asylum. Having fled or been released, on the 14th day of the present month he again attempted to wrestle the staff of office, with which he was being restrained, from the hands of the Mayor, threatening him that he would die that very night, accusing him of being a thief and proffering other offensive words, and insulting other individuals with whom, for no apparent reason, he was upset. He was later found with a knife for slaughtering pigs and a whetting stone commonly used by weavers, his profession, for which he was arrested and still today is being detained in the town prison. We are therefore expecting from the Hospital to keep him locked up, for beyond

¹² AHSCSP *Manicomio Dementes* I.

the confines of the Hospital he goes back to what he is used to, his spells of madness, and it is the only way to keep the peace of the town.¹³

Unlike Joan, a glutton and a drunkard, Miquel is assumed to be mad because of his blasphemy, his anger and his threats of violence. These are common features in insane's admissions before 1850 in Barcelona. Madness is less obsession, mania or delusions than behaviour and violence, behavioural *excess*. May went to the Hospital with a certificate of the local priest and another from the local physician. But the Board only took any notice of the first. The fear of cases such as those of May and Rocamora has to do with uncontrolled violence, which was also common in barrack rooms, and related to the excess of eating, drinking and lechery, which was the reason given for shutting away the father of Narcisa de Cabriol, a young lady from Arenys de Mar, in an asylum for more than two decades (COMELLES, 2008).

The relationship between *excess* and *madness*, which might be understood from within scholastic rationality, is also linked to a naturalistic notion of capital sin. Even prodigality could be interpreted as insanity (GOTMAN, 1995). Not so surprisingly, the admission application of those guilty of capital sins classify them as insane and, therefore, capable of being cared for and cured. The *civil* diagnosis is exculpatory, and the fact that they are returned to the community highlights the pressure brought to bear for cases to be resolved. The notion of *excess* has nothing to do with *statistical normality*. It is the product of an *ethnographic gaze that evaluates acts in their local context* and that is connected to the Hippocratic naturalism. *Excess* is a transgression from civility and is perceived as madness, as the fruit of the beast, and the beast is irresponsible and not attributable. Despite the handcuffs and the cages, the wards for the insane are not a prison but a refuge.

¹³ AHSCSP *Manicomio Dementes I*.

Excess, nosography and fears

In spite of the secularization of European societies and the advance of the medicalization process, some elements of scholasticism and Hippocratism have reached us in quite a contradictory fashion. The dissolution of Cartesian dualism and the secularization of European societies have not reinforced the relativization of attitudes and behaviours; rather the Christian *diatēia* is replaced by a new scientific rhetoric that seeks to support some values as opposed to others and which converts *moral excess* into *deviation* from the statistic norm.¹⁴ In day-to-day language, invoking moderation or political centrality leads to the notion of temperance between political *excesses* and *excesses* of the flesh.

Hippocratic *diatētes* was relativist and required physicians to adapt their advice to the material and cultural contexts of their patients. Although the sense was universal, practice had to be relative. Medical and Christian rhetoric's share the same conception of universal *diatētes* as political liberalism: not at all relativist, strongly normative and homogenizing. One of the features they share is the persistence of scholastic thought despite the hegemony of the experimental method and positivism, which also share the same moral fundamentalism in their struggle for truth. Since the elites of the West have often been educated in Christian colleges, their embodiment is not alien to scholasticism and conservative morality that is easily projected on whatever activity. In a recent book Richard Klein writes:

Recently, it has become un-American to be Epicurean, to consider pleasure, even moderately indulged, to be the highest good. An old strain of American Puritanism, to which Jefferson was immune, if not allergic, has become the new morality. Dressing itself up in the language of public health, this new morality views the least indulgence in adult pleasure as the sign of a nascent habit on the way to becoming a dangerous compulsion (KLEIN, 2010:19).

¹⁴ About the relations between normal and abnormal see Canguilhem (1971), and related with obesity Hacking (2005, 2005^a).

In anthropology, medicine and psychiatry, concepts such as *perversion*, *maniacal rage*, *degeneration*, *savagery* or *barbarism* were defined and redefined without the least respect for the critical distance that we might expect of scientific thinking.¹⁵ They make up a cluster with the elements of *excess* related to the more *animal* aspects of man: gluttony, lechery, violence, rage, agitation, and the abuse of alcohol and narcotics. In the classical nosographies, we can find voyeurism, paedophilia and homosexuality on the same level of pathological intensity – they are all sins – and now we can see the same looking at *eating disorders* (anorexia, bulimia and obesity) (GRACIA & COMELLES, 2007), or other concepts such as *social phobia*. Common terms in 19th Century psychiatric nosographies such as *rage*, *agitation* or *calm*, or the concept of *psychopath* in the 20th century characterized by moral coldness highlight the embodiment of sin by scientists through the following parallelisms:

Lust / perversions
 Gluttony / obesity, alcoholism
 Envy / paranoia
 Wrath / criminal violence
 Pride / megalomania
 Sloth / amotivational syndrome (related to addictions)
 Greed / compulsive obsession

In the 19th Century, excess and madness excuse and de-responsibilize the insane but not the community. The to-day nosography excuses the community and invokes individual somatic aetiologies, personal vulnerability and so on.¹⁶ To a great extent, the somatization of behaviour highlights human animality, violence, gluttony and lust, which do not excuse the individual but are perceived, as the product of a perfectly rational will. Jekyll and Hyde were both rational. However they generate irrational fear in a rational society. Jekyll looking to be some feature of God, Hyde because he needed to avoid moral to get his lust on hand.

¹⁵ About the empirical roots of the concept of perversion in psychiatry see Lantéri-Laura (1979).

¹⁶ This is the case of the well-known DSM handbook in psychiatry.

In the late sixties of 20th Century Kubrick's *A Clockwork Orange* depicted *ultra violence* in similar terms.

Cholesterol, obesity and moral panics

After decades criticizing the subjectivity present in the classical psychiatry or in psychoanalysis, psychiatry regards to day itself as a mere subordinate speciality of the hegemonic medical model. However, psychiatrist can feel themselves as scientists, like common doctors, and not quacks. This evolution enhances their feelings and their beliefs that psychiatric nosology is largely somatic. This process has benefited from the fact that the debate about the body – in both its physical and symbolic dimensions – has become *central* to interpersonal relations, even if reduced to clinical individual variables in modern Western society. However, the look on society is now statistically based, not ethnographically based on the *local* worlds as Hippocrates suggested. Norms, prescriptions and responsibility are for the individuals and are universal, without local nuances. The rigidity of norms, of *diates* founded on somatic and non-relativistic parameters do not allow the understanding of the individuals in social or cultural specific contexts. The medical and psychiatric language has to be the most simplistic as possible, avoiding complexity in a more and more complex world. In some sense the universality of the Christian sins applies to somatic and mental illnesses.

A good example of and case study is *cholesterol*.¹⁷ First it was a somatic indicator as many others in current blood exams. In a second step it was statistically correlated with some health risks. Correlate means that a connection can be established between two variables, not necessarily that there is a direct causality. However, the indicator takes on a symbolic value, induced by scientific practice itself, which provides drugs that are called into question to a greater or lesser extent and that will bring it under control, and a nutritional catalogue that can limit its intake. The prevention

¹⁷ See David (2011 *in that book*) about the genealogy of cholesterol in the current world.

strategy, then, converts the indicator into the cause and prescribes its control and reduction by means of moral figures: to reduce it means to avoid *excess* and to embody *temperance*. In some way it means to accept the prescriptions of experts and to assume self-discipline in front of any temptation. Danacol commercials are sympathetic with the *excesses* of the social actors (the term highlights the weakness of the individual will and portrays it in the form of being tempted by the pleasure of eating), but far from condemning the sin, the commercial is understanding and provides a solution that allows some pleasure, if you eat Danacol regularly. There is no society, only individuals who are solely responsible for their own well-being or discomfort. The political narrative of liberalism tends to present the world in this light and sin will not be pardoned. There is no need to confess a pardonable sin. You only need Danacol.

Nevertheless, what happens if the problem affects not adults but kids, as is often the case with eating disorders, which involve an *excess* of fasting in anorexia and an *excess* of gorging in bulimia, overweight and obesity. Far removed from the relativism of the classical constitutionalists such as KRETSCHMER (1947), current medicine and psychiatry conceive what had been a symptom – anorexia or putting on weight as a result of a variety of pathologies – as pathology of the willpower.¹⁸ So, can children be responsible for their own behaviour? The question is somewhat paradoxical in cultural and legal terms. Kids are not full legal subjects, because they enjoy the protection of their guardians, and they do not make their own food; they have it cooked and given to them. So, who is responsible for the *excesses* that lead to child obesity? Finally, obese kids are the victims of an image that generates discrimination, exclusion and the emergence of particularly interesting language: *vaca* (cow), *foca* (literally seal), *balena* (whale), *bestia* (beast), *golafre* (glutton). In Catalan the first four terms are feminine and the last masculine. Obesity, however, is common to both boys and girls.

¹⁸ See Berlant (2010) on the ambiguity of “health” in the context of the debate about obesity.

The increase of obesity in Western countries has been related to the ease of access to food, its relative economy, and important social changes – among others, the so-called sedentarization – and the use of the BMI, an instrument that is by no means relativist, to establish the criteria for obesity has led to it becoming a label for illness. Biomedicine recognizes that only one in every ten cases is a somatic disease. The others are *essential* and are attributed to the *excess* of eating – in fact gluttony-, and in a second level in children the *excess* of sedentarization. Hippocrates already invoked both reasons in any case on the basis of a relativistic point of view. However, the present medical narrative is absolutely *moral* to the extent that it lays the blame on the willpower of individuals, their gluttony in fact, and their inability to repress their greediness, the sin of eating for pleasure. Now, the WHO has announced the epidemic of obesity that affects one billion humans as a big drama. Having implicitly condemned lust in relation to the pandemic of AIDS, the health sector is now embarking on a crusade against the sin of eating, gluttony, and at the same time a crusade against the sin of voluntary fasting, anorexia. Excess, sin, will, irrationality. *The beast in me?*

Sources

ARXIU HISTORIC DEL HOSPITAL DE LA SANTA CREU I SANT PAU
FOLDERS *Dementes- Gobierno 1*

References

- AQUINO, Tomas de (1955) *Summa teologica*, Madrid: Biblioteca de Autores cristianos.
- ATTERBURY, Adams, Allen *et alii* (1795) *Family Lectures or a Copious collection of sermons*. London: Printed for T. Longman *et alii*.
- BERLANT, Lauren. (2010) “Risky Bigness. On Obesity, eating and the ambiguity of health”. In METZL, Jonathan, KIRKLAND, Anna (eds), *Against Health: How Health became the New Morality*. Nueva York & Londres: New York University Press, 26-39.

- BROWN, Peter (1993) *El cuerpo y la sociedad: los hombres, las mujeres y la renuncia sexual en el cristiano primitivo*. Barcelona: Munchnik Editores.
- CANGUILHEM, Georges (1971) *Lo normal y lo patológico*. Buenos Aires: Siglo Veintiuno Argentina.
- COMELLES, Josep M. (2006) *Stultifera Navis. La Locura, el poder y la ciudad*. Lleida: Milenio.
- COMELLES, Josep M. (2008) "La sombra del miedo". In FERNÁNDEZ, JUÁREZ, Gerardo, PEDROSA, Juan M. (eds.), *Antropologías del miedo. vampiros, sacamantecas, locos, enterrados vivos y otras pesadillas de la razón*. Madrid: Calambur, 79-118.
- GARCÍA BALLESTER, Luis (1995) *Artifex factivus sanitatis*: health and medical care in medieval Latin Galenism. In BATES, Donald G. (ed.), *Knowledge and the Scholarly Medical Traditions*. Cambridge: Cambridge University Press, 127-150.
- GARCÍA GUAL, Carlos (1986) Sobre la dieta. Introducción. In HIPOCRATES DE COS (comp.), *Tratados Hipocráticos III. Sobre la dieta. Sobre las afecciones. Sobre el uso de los líquidos. Sobre el alimento*. Madrid: Gredos, 9-17.
- GRACIA, Mabel & COMELLES, Josep M. (2007) *No comerás*. Barcelona : Icaria.
- GRACIA, Mabel, BERNAL, Mariola, CASADÓ, Lina, COMELLES, Josep M. et alii (2007) *Els trastorns alimentaris a Catalunya. Una aproximació antropològica*. Barcelona: Generalitat de Catalunya.
- GRASSET, Joseph (1882) *L'Art de Prescrire. Preleçons au cours de Thérapeutique 1882*. Montpellier: Typographie de Boehm et Fils.
- GOTMAN, Anne (1995) *Dilapidation et prodigalité*. París: Nathan.
- HACKING, Ian (2005) *Normalisation: l'épidémie obésité*. Paris: Collège de France.
- HACKING, Ian (2005) *Philosophie et histoire des concepts scientifiques*. Paris: Collège de France.
- HIPOCRATES DE COS / LOPEZ FEREZ, G. (1986) *Tratados Hipocráticos III. Sobre la dieta. Sobre las afecciones. Sobre el uso de los líquidos. Sobre el alimento*. Madrid: Gredos.

- JOHNSON, Samuel & WALKER, John (1828) *Dictionary of the English Language*. London: William Pickering, Chancery Lane, George Cowie and Co. Poultry.
- KLEIN, Richard (2010) "What is Health and How Do You Get It?" In METZL, Jonathan, KIRKLAND, Anna (eds), *Against Health: How Health became the New Morality*. Nueva York & Londres: New York University Press, 15-25.
- KRETSCHMER, Ernst. (1947) *Constitución y carácter: investigaciones acerca del problema de la constitución y de la doctrina de los temperamentos*. Barcelona : Editorial Labor.
- LANTÉRI-LAURA, Georges (1979) Conditions theoriques et conditions institutionnelles de la connaissance des perversions au XIX siècle *L'Evolution Psychiatrique* 44 (3) 633-663.
- MILLER, Timothy S. (1997) *The Birth of Hospital in the Byzantine Empire*. Baltimore: Mr., The Johns Hopkins University Press.
- MOLINER, María (2002) *Diccionario del uso del español A-H*. Madrid: Gredos.
- RUBIES, Joan-Pa. (2007) *Travellers and Cosmographers. Studies in the History of Early Modern Travel and Ethnology*. Aldershot: Ashgate.
- SEVILLA, San Isidoro de (1993) *Etimologías. Edición bilingüe preparada por José Oroz Reta y manuel A. Marcos Casquero*. Madrid: Biblioteca de Autores Cristianos, 2 vols.
- TEMKIN, Owsei (1991) *Hippocrates in a World of Pagans and Christians*. Baltimore: Mr., The Johns Hopkins University Press.
- WEBSTER (1996) *Webster's Encyclopedic Unabridged Dictionary of the English Language. New Revised Edition*. New York: Random.

FROM SOFT DISCIPLINE TO HARD PLEASURE: "HEGEMONIC BODY IMAGES" IN NORTH INDIA

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Introduction

Is there such a thing as an "ideal" male body? Can one speak intelligently of a "hegemonic body ideal" in France, or Europe, or India? And if such an ideal can be identified for certain times and place, can one describe the ways in which it changes? In this paper I set out to answer these questions in relation to the culture of north India. On the face of it, the question itself is absurd, due to India's fabled diversity. In the religious and literary texts of India, in its political and military history, and in its public imaginary nourished by ancient Indian concepts as well as the newest transcultural trends, we find an astounding array of idealized male bodies: the emaciated yogi, the bulky wrestler, the divine, cross-dressing seducer, the tireless warrior, the wiry farmer, the muscle-bound Bollywood star, the chubby masculine deity . . . the list goes on and on. Given such diversity, does it make any sense at all to speak of a "hegemonic male body image"?¹

Similar problems were faced by Connell and his associates in the early 1980s, when they developed the concept of "hegemonic masculinity." Something about this idea appealed to the intellectual Zeitgeist, and to the growing interest in gender studies, queer studies, and so on, and the idea was taken up by a large number of scholars in different fields. In a recent and useful article, Connell and Messerschmidt (2005) have reviewed the numerous criticisms made of the concept, and revised it accordingly. One of the central criticisms was that the notion

¹ With many thanks to Meenakshi Gaur for her generous assistance.

of hegemonic masculinity is essentialist and universal, as if the aggressive, muscular, incommunicative “Rambo” figure of the American public imaginary in the 80s was *the* form of hegemonic male for all times and places. According to the critics, such a universalizing concept does not take sufficient account of the numerous, alternative masculinities that can be identified and traced for various cultures and periods. Referring to the work of Behnke and Meuser (1998), the authors point out that:

(b)ecause every ethnography discovers a distinctive gender culture, every life-history study uncovers unique trajectories of men's lives, and every structural analysis defines new intersections of race, class, gender, and generation, it is logically possible to define “a thousand and one” variations of masculinity (CONNELL and MESSERSCHMIDT, 2005:845).

Connell and Messerschmidt agree, and argue that hegemonic masculinities always arise in plural and hierarchical contexts, and that such multiplicity was a crucial part of their concept right from the beginning. The task of the analyst is not to enumerate a list of ahistorical and essential traits that go to make it any particular form of masculinity, but rather to analyze the processes by which it becomes (or does not become) hegemonic. Hegemonic masculinity does not refer to the possession of traits, but rather to a certain kind of performance:

Masculinity is not a fixed entity embedded in the body or personality traits of individuals. Masculinities are configurations of practice that are accomplished in social action and, therefore, can differ according to the gender relations in a particular social setting (ibid: 836)

The fundamental feature of the concept remains the combination of the plurality of masculinities and the hierarchy of masculinities... Also well supported is the original idea that hegemonic masculinity need not be the commonest pattern in the everyday lives of boys and men. Rather, hegemony works in part through the production of exemplars of masculinity (e.g., professional sports stars), symbols that have authority despite the fact that most men and boys do not fully live up to them (ibid: 846).

So it seems that it is indeed possible and legitimate to ask if there is such a thing as a “hegemonic male body” at a given time and place, as long as we bear in mind that such a hegemonic

body is a *performed* body rather than an assemblage of traits, and that it normally arises in a situation of multiplicity, where numerous body ideals are available.

But still, when we turn to India, we are confronted with such a range of “body ideals” that the task of locating a hegemonic one seems rather Quixotic. How to proceed? I think it is safe to assume that this diversity of body ideals is not chaotic, and that it is related to India’s notoriously complex social system, with its multiplicity of languages, religions, sects, castes, tribes, and classes. But how can we begin making connections between the range of body images on the one hand, and their locations in social space on the other? For me, the best place to begin to understand Indian diversity is the scheme devised by McKim Marriott (1976). His central project was, and remains, to generate a theoretical framework that explains how India’s social and cultural forms are generated through social interaction, by using concepts derived from the classical Indian sciences like Ayurveda, astrology, mathematics, and so on.² Marriott takes the four classical Indian *varna* or classes (the German word *Stand* is actually a better translation) as a heuristic model, and tries to describe an ideal transactional strategy for each. Given their attributes, most of which they attain at birth, the Brahman priest, Kshatriya warrior, Vaishya merchant and Shudra farmer each have a characteristic strategy for maximizing their welfare in this life and the next. Can we say that they have a corresponding body type as well? In the popular imaginary as well as in classical iconography and literature, the body of the Brahman priest, living as he does on a vegetarian diet and devoting himself to prayer and study, is distinguished by its lightness and purity, while the body of the Kshatriya warrior, who eats meat and engages in righteous violence, is active and strong. In popular images the body of the

² It might be objected that this agenda is deeply Hindu, and that it leaves out Muslims and other minorities who make up a large part of Indian society. But this is an anachronistic objection; that there is plenty of evidence of a syncretic Hindu-Muslim civilization that took shape in North India under the largely benevolent gaze of the early Mughal empire; and that the sharpening of the contemporary Hindu/Muslim divide is a relatively recent phenomenon.

rich merchant is heavy, tending toward what one might now call “obesity”, while the body of the Shudra farmer, shaped by hard physical labor, is wiry and hard. Of course one could say that these are nothing more than common stereotypes; but stereotypes often have a grain of truth. More importantly, these bodies are not so much “hegemonic ideals” as they are stereotypical outcomes of class-based lifestyles; manifestations of prescribed forms of dharma, what Marriott calls “codes for conduct.”

The Indologist Heesterman has argued that the ideal of renunciation gradually became hegemonic in the Indian tradition (1985), and one could also argue that a certain male body ideal goes along with it, so that in the end, the emaciated body of the yogi becomes a more-or-less universal ideal, appealing to all four classes. But where do Muslims fit in this picture? What about Christians, Parsis and Sikhs? What about India’s millions of tribals? Or, as students of India are wont to say, what about the South? Even in the relatively limited region of the Western Himalayas where I have conducted most of my fieldwork, there are two categories of Kshatriyas: the sophisticated and aristocratic Rawats, and the hard-drinking, hard-fighting Khunds. The men of the former group tend to be much more manicured, controlled, and carefully dressed; while those of the latter group pride themselves on their rough manners, lack of grooming, and simple clothes, and there are corresponding body ideals as well (see SAX, 2006).

It seems that we are faced once more with an extreme diversity of male body ideals in India. What to do? How can we approach this problem? I think that we should do so by identifying and analyzing ideal body types that are inflected neither by the religious concepts of purity, pollution, renunciation and so on, nor by the minutiae of caste differentiation. We should identify and analyze cases where the male body, in itself and for itself, is the central value; where it is valued and cultivated for its own sake.

The Wrestler's Body

Perhaps the most prominent such case is the *pahalwan*, the north Indian wrestler. We are fortunate to have a superb ethnography of wrestlers, published in 1992 by Joseph Alter. He reports that wrestlers proudly reject social exclusion based on caste or religion: anyone may join one of their wrestling "clubs," and indeed the physical intimacy required by wrestling, along with associated practices such as mutual massage, constitutes a critique of the caste hierarchy with its principles of physical pollution and purity, and the rules against physical contact resulting from these principles. In the context of the wrestlers' clubs, a member of the high-ranking Brahman caste may well massage the feet of an elder wrestler from a low caste, since hierarchies of age replace those of caste. More importantly, the ideal body is cultivated for its own sake, with strict attention to exercise, diet, sleep, sexuality, etc, and for reasons of health rather than religion, sexual vanity, or politics: women are rigorously excluded from this male domain. For wrestlers dedicated to the cultivation of the male body, the path to somatic excellence involves mental, spiritual, and moral discipline, as well as bodily training. In short, the discipline of wrestling is holistic. These traits are shared with classical Indian yoga, which informs the underlying principles of the wrestler's physical exercise (ALTER, 1992: 94).

Plates 1-3 show the bodies of wrestlers, taken from wrestling magazines. The ideal wrestler's body is certainly characterized by its strength and bulk, but it is also a supple body, flexible and taut, and these qualities are reinforced by the wrestler's exercises, diet, and practices such as massage. Note, in particular, that these bodies do not correspond to the sculpted bodies typical of Bollywood films and the fashion industry, with their well-defined muscles and flat stomachs.) Wrestlers believe that in order to develop an ideal body, it is of the greatest importance to retain their semen. Indeed, it is a common belief amongst Hindus that semen contains the essence of life, and this belief is reflected in

Indian medicine, mythology, and religion as well.³ Alter argues that for wrestlers, semen is:

the very cornerstone of their somatic enterprise. It is the source of all strength, all energy, all knowledge, all skill... It would not be an exaggeration to say that the single most important aspect of a wrestler's regimen is his subscription to the absolute tenets of *brahmacharya*: celibacy and self-control (1992:129).

As a result, wrestlers are deeply opposed to masturbation, and are greatly concerned with nocturnal emissions as well. Above all, one must avoid sexual thoughts, and the company of women. As one wrestling guru quoted by Alter puts it,

One should not look at a woman, never speak to a woman, never touch a woman, never think about a woman, never listen to a woman, never be alone with a woman, never joke around with a woman, and, of course, never have intercourse with a woman... Sensuality of any kind, and heterosexual lust in particular, is to be avoided at all costs (ibid: 130)

If one fails to follow this particular regimen, one is left with a weak body and the telltale signs of hedonism: a dark and sallow complexion; a drawn face; sunken eyes; a thin, "dried-out" physique, and stooped shoulders (ibid: 134). As Alter puts it, one difference between bodybuilding and wrestling is that, for the former,

the body is regarded as a mere flesh and blood object, it is conceived of as a lifeless thing which can be molded. It can be disciplined, sacrificed, branded, tattooed, reportioned, and developed through exercise. The mind (disembodied thought) is always regarded as the master of this game of control (ibid: 91).

But in Hindu "schemes of discipline" it is:

impossible completely to objectify the body. The end result of regimentation and disciplined exercise in India is therefore quite different from its Western counterpart. Rather than a "nightmare of totalization" where

³ The topic has been widely discussed. Both Bottero (1991) and Paris (1992) contain good summaries of the literature.

the body is subjected to a refined and detailed biomechanics of health and fitness, in India one has a situation where discipline endows the body/mind with a heightened sense of subjective experience and personal self-awareness. That is not to say that in India the individual experiences discipline as personal emancipation. In India, however, discipline is not simply manifest as an objectification of the body but equally as a subjectification of the self... In India a person's individuality is constructed through the development of his or her body. In the West disembodied individuality is imposed onto a generic biological human form (ibid: 92-93).

Krishna's Erotic Body

As already mentioned, such ideas are widespread in India, and it has even been suggested that semen-loss anxiety is a typical North Indian culture-bound syndrome, a topic to which I shall return below. But remember our starting point: that ideal male body types in India are multiple and diverse. For example the divine body of Krishna, who is a hyper-erotic figure, is consistently valorized in the Indian tradition, even though it is in many respects the polar opposite of the wrestler's body. Krishna is, of course, a complex figure, and not all of the traditions associated with him are erotic: the Krishna of the *Mahabharata*, for example, is rather stern. Nevertheless, some of the most prominent of Krishna's devotional and liturgical traditions do indeed celebrate his erotic exploits, and in particular they focus on his body, which is an object of devotion for the worshiper as well as for the many women with whom Krishna has an erotic relationship. What I wish to stress is that this particular body, which is an explicit object of eroticized, spiritual contemplation, is radically different from the body of the wrestler, as well as from the body of the fashionable young man of the contemporary Indian metropolis. It is a dark bluish color – the color of rainclouds, as the poets put it – and is not hard and muscular but rather soft, supple, and flexible. The texts recommend meditating upon this body with all its physical details, but it is not its strength or masculine power that are emphasized, but rather its softness, its fragrance, its lustre. For example in the eleventh Canto of the classic Sanskrit song *Gita Govinda*, which has been used

liturgically in India for centuries, and arguably the most influential of such texts, he is described in the following way:

The soft black curve of his body was wrapped in fine silk cloth,
Like a dark lotus root wrapped in veils of yellow pollen.

...

Earrings caressing his lotus face caught the brilliant sunlight.
Flushed lips flashing a smile aroused the lust of passion.

...

Flowers tangled his hair like moonbeams caught in cloudbreaks.
His sandal browmark was the moon's circle rising in darkness.

...

His body hair bristled to the art of her sensual play.
Gleaming jewels ornamented his graceful form.⁴

Krishna's eroticized body even crosses the border between male and female in some of this literature, for example when he engages in playful cross-dressing with his lover Radha, or in at the climactic twelfth canto of the *Gita Govinda*, where Krishna submits to Radha as her "slave" and she rides on him during intercourse.

Paradoxically, for many Krishna sects the only way for a man to realize such ideas in his personal, spiritual life is to become a celibate renouncer who takes on a female persona in relation to Krishna, and for whom these images are objects of meditation, but never of practice (see HABERMAN, 1988). This is after all a religious tradition, and most of its branches promote a rather conservative sexual morality. The important point here is that Krishna's body fits into this moral system as an object of contemplation.

The Sexualized Male Body

But let us leave the realm of esoteric religion and return to our spectrum of male body ideals. We can add another one that, like the body of the wrestler, the yogi, and Krishna, emerges within Indian culture and is celebrated by it. This male body is

⁴ Gita Govinda, Canto XI, song 22, sung with Raga Varadi. From Miller's 1977 translation.

healthy, fully sexual, but human and not divine. It is the male body as represented in the discourse of the *Majmawalas*, “street performers” who sell medications on the side of the road, in busy bazaars throughout north India, Pakistan and Bangladesh. The word *majma* means “performance,” and these men are called *majmawalas* or “performers” because they sell their wares in a very performative manner, much like the “Snake Oil Salesmen” in the old Wild West of north America. I conducted research on them in Delhi during the winter of 2009/2010, and when I asked them what *majma* meant, they said, “Professor Sahab, you do *majma* every day, whenever you lecture to your students!”

It turns out that they mostly sell male potency medications, what one might call “indigenous Viagra.” Predictably, their performative sales routines contain explicit language and sexual humor, so that young boys and females are rigorously excluded from listening. What the *majmawalas* have to say about relations between men and women, however, did not strike me particularly sexist, and might even be seen as “progressive” in a certain way. They say that Allah made both women and men as sexual beings, so that there is therefore nothing wrong with sex inside of marriage. Those who think that sex is “dirty” are simply uneducated fools. But women are more highly sexed than men: as the *majmawalas* say, “they have two orgasms, whereas men only have one” – and female desire or *kvaish* must be satisfied. How does a man satisfy his wife? By taking the time to listen to her, by allowing sufficient time for sexual foreplay, by never forcing himself on her, by not going to sleep immediately after intercourse, but instead talking to her. In short, the discourse of the *majmawalas* is thoroughly moral, and not just somatic. But of course the *majmawalas* are also selling a product, one that is meant to increase the potency and stamina of its users. In fact they have a great deal to say about the size and shape of the penis, as well as about stamina, desire, sexual competence and knowledge, and health in general. But there is no “ideal body image” here, only a kind of ideal penis, an ideal level of sexual performance that, they promise, can easily be achieved if one takes their medications.

Many of the *majmawalas*’ clients have anxieties about semen loss. A concern with semen retention and loss is also typical of

wrestling and yoga. Alter calls semen retention the “single most important aspect of a wrestler’s regimen.” All of these systems regard semen as the source of both physical and intellectual power. A standard part of the *majmawalas*’ routine, from Delhi to Dhaka, is to pour a tiny bit of water into a handful of seeds, which soon congeal into a thick rubbery substance that can be displayed to the audience. They call these seeds *lajjavati*, “preserver of men’s honor”, and it is a crucial ingredient in their medications, which are meant, among other things, to make one’s semen thicker.⁵

A number of Indian psychologists, and some western ones as well, have argued that an excessive concern with semen loss is neurotic, and they have labeled it the “*dbat* syndrome” (*dbat* is a word for semen). *Dbat* syndrome is even listed in the Diagnostic and Statistical Manual, along with other culture-bound syndromes. Certainly, anxieties about semen loss are widespread. When for example the *majmawalas* list the presumed symptoms of semen loss, the men standing in the circle often nodded and whispered “*Dbat... dbat... dbat*” to each other, without any prompting. Clearly, they are very familiar with the idea. Here is Mumford’s list of symptoms:

(C)omplaint of loss of semen in association with multiple somatic symptoms, hypochondriasis, fatigue, physical weakness, anxiety, loss of appetite, guilt, and sometimes impotence or premature ejaculation.

The *majmawalas* amongst whom I worded would certainly agree with this list. At the same time, they would disagree with the rest of the paragraph, which reads as follows:

⁵ The latin name is *Mimosa pudica* (in English the synonyms “Sensitive plant” and “Touch-me-not” are given). The seeds are said to be useful in “weakness of sperm” (*sukradaurbalya*) (SHARMA, 1981-98, Vol. II: 750 ff.) Nadkarni, (1994: 799) tells us that this plant is originally from Brazil, but it is known and used in Ayurveda since at least the early 15th century since it is described in the so-called *Kaiyadevanighantu* dating from between 1400-1450. (Thanks to Anand Chopra for this information).

The 'syndrome' is reported to be more common in recently married men, in men of lower socio-economic status, in rural areas, and in men who belong to a family that has conservative attitudes towards sex (MUMFORD, 1996:163).

My *majmawala* respondents, by contrast, say that the poor, especially the laboring poor, have fewer sexual problems than the rich or middle class, because they have strong, fit, wiry bodies. They have no money to go to the movies or take a holiday, and so sex is their only pleasure. Their main problem is lack of privacy, i.e. they are afraid of being "caught in the act" by their children, and this anxiety sometimes affects their performance.

The *dhat* syndrome is an extremely controversial topic, and far too much has been written about it, both "pro" and "con," for me to summarize in this chapter. I simply wish to make two points. First of all, it seems likely that with *dhat* syndrome, a particular understanding of sexuality, a way of living in a male body, has been medicalized and pathologized, simply because it does not correspond to "modern" or "western" or "scientific" understandings of such things. In any case, we have here another male body type, but it is not an ideal body; rather, it is a body that has been pathologized by modern psychology.

Secondly, I would like to note the response of the psychologists and psychiatrists to semen loss anxiety, which is to treat it as a purely somatic phenomenon. In the psychological and psychiatric literature, as well as in my interviews with practicing psychiatrists in Delhi and elsewhere, it became clear that the usual therapeutic intervention by these modern, scientific "sciences of the mind" involved educating the patient, informing him that masturbation and nocturnal emission are very common and that semen loss will not lead to all the ill effects that they dread, and that these things should be regarded as purely physiological matters (e.g. MALHOTRA and WHIG, 1975; MUMFORD, 1996). In doing so, they take sexuality and the male body out of the holistic realm of morality, ethics, and religion, and place it firmly in the realm of the material. I shall return to this theme at the end of this chapter.

A Hegemonic Body Ideal?

In recent years a new body ideal has come to the fore: hard and muscular, with cut muscles, a flat stomach, and little or no bodily hair. It is deeply entangled with modern media, especially consumer advertising and Bollywood films, and it is not simply “Western,” but clearly a transcultural body, having strong affinities with male body ideals circulating in the global public sphere and not tied to any particular “culture”. Is this the “hegemonic body ideal” of contemporary north India? It is certainly modern and fashionable; as Alter (1992) says, it is associated with “fast motorcycles, high-tech sound systems, digital watches, and so forth” (p. 56). But not everyone is impressed. For example, the wrestlers denigrate the bodybuilders, saying that they have:

“balloonlike bodies” which have form but no substance. They smirk at narrow waists that would snap in two at the slightest touch, and grimace at protruding tendons wrapped tightly by the work of an iron machine... while the bodybuilder is seen as bits and pieces of random flesh, the wrestler's body is a smooth, integrated whole... (57)

The new body ideal seems to have come to the fore in the advertising of the 1990s. The classic case was the campaign for Kama Sutra condoms, one of the most successful advertising campaigns of modern times, thoroughly documented by William Mazarella in his 2003 study of the Bombay advertising industry. The advertisers hit on a winning strategy, combining appeals to sexual pleasure that included beautiful bodies in erotic poses with a sales pitch and a product name – Kama Sutra – that emphasized Indian Tradition. At last, one could be modern and erotic while still be authentically “Indian.”

Other products like underwear, anti-perspirants, clothing, motorcycles and so on followed suit, and in the early 90s there was a clear shift in Indian advertising toward a new kind of male body. I have looked at a number of television advertisements for underwear, perfume, condoms, and clothing, trying to understand how new kind of male body changed emerged during past few decades. The trajectory of change over time in the content of advertisements for automobiles and motorbikes suggests a

movement from portraying males as good citizens and family men to erotic, individualist consumers. An ad for a moped from 1991 for example shows a middle-class clerk in trouble with his wife because it takes so long to get home, but once he buys the moped his life improves, and his wife and child are both seen riding it. The ad is accompanied by Hindi poetry. A year later, Bajaj motorcycles show a whole series of quasi-nationalist scenes accompanied by stirring music, and a Bajaj ad from 1997 is also rather nationalist, showing the man's various roles as father, son, lover, etc. A 1999 ad for Tata automobiles is a complex little mini-opera where a man picks up a beautiful girl in his car, takes her home, throws her flowers secretly at night, and is chased off by her father with a shotgun. Later there are romantic scenes on a lake, dancing by candlelight, a church wedding, and finally children, but then the music slows down, the film rewinds, and the man in the car realizes that it was all a fantasy or a daydream, and the girl is still standing there, waiting for a lift. Interestingly, all of this takes place to the old Lobo song "Baby I want you to want me."

In more recent advertisements the eroticized, individualist consumer comes to the fore: one ad for Suzuki motorcycles shows a woman's hands stroking something – one can't quite tell what – and whispering to the male driver that "You drive me crazy" while the voiceover speaks of "stunning looks" and "full power" along with the sound of erotic sighing in the background. At the end of the advertisement, the woman says in a throaty whisper, "Once more!" A 2009 advert for Honda motorcycles begins with the Bollywood star Hrithik Roshan, accompanied by very contemporary music, standing in plane hangar next to (his) helicopter. He climbs onto the Hero motorbike waiting for him, and nonchalantly drives through a cyclone and an ocean wave on his motorbike. He is a tough guy, a loner, and the refrain is "I'm comin' out!"

In order to be certain about long-term trends in the advertising industry, one would have to see far many more advertisements than I have, and analyze them over a longer period. Still, those I have seen powerfully suggest not only the development of a new male body ideal, but also of a new type of consumer: more

individualistic, less committed to family and community, more involved with casual sex and not with long-term relationships.

When one turns to the advertisements for underwear, after-shave and condoms, the message is clear: that the new male body ideal attracts women and leads to sexual pleasure. Moreover, one attains this physique neither through the discipline of the yogi or the wrestler, nor by taking the medicines of the *majmawala*, but rather by appropriate consumption: the right underwear, the right after-shave, and the right clothing, draped on a “buff,” sculpted body with little or no body hair. According to Alter, for the wrestlers, proper clothing consists of loose-fitting cotton garments that allow the body to breathe, and they object to tight, synthetic clothes. Wrestlers are deeply critical of young men obsessed with fashion, and especially of Hindi films, with their blatant eroticism that can lead directly to loss of semen through masturbation or nocturnal emission. For them, the modern world is a world of seduction: movie halls, liquor stores, and commercialism. We might call this consumerism, but for the wrestlers it is the world of the senses, contrasted with the serene self-control of the *akbhar*. As one wrestling author put it,

they do not even remember that their bodies are the product of the earth. We see that they are reticent to pick up their playful, dust-covered children, for fear of soiling their fancy, tight-fitting, mill-cloth clothes. And yet these same people blindly smother their children in powder and perfume. They do not realize that the wrestler who grapples in the earth, the farmer who plows the earth and the child who plays in the earth are all far healthier than those who are alienated from the soil (ALTER, 1992:247)

However the wrestlers seem to be fighting a losing battle, as there has been a recent and massive growth in India of beauty salons where men are waxing their bodies, building their muscles, and putting on tight pants when they leave. In a cover story from the magazine *India Today* in October 1997 (“Craze for Abs”), the head of plastic surgery at a prominent teaching hospital in north India is quoted as saying that a decade earlier, patients were mostly women, but that now men constitute one-fourth of the clientele. Another doctor from Mumbai reported that he sees “at least three times more male cosmetic surgery patients than

(he) did five years ago (DANGOR *et alii*, 1997). A doctor from Delhi reported that “Three years back, ninety per cent of our patients were women, [but] today, 40 per cent are men”. An AC Nielsen survey of one thousand men in four large Indian cities, published the month before, said that over seventy per cent of India’s urban males visit a salon at least once a month for hairstyling, facials and skin-lifting treatment. Cosmetic surgery for men is on the increase. “Muscle sculpting” and “facial rejuvenation,” “abdominal etching” for flat stomachs, “fat transfer” from one part of the body to another, “body contouring” for removing wrinkles (KAUR, 2010). But while the Indian media reports on this trend as if it were a Tsunami, the statistics suggest that it is more like a slowly rising tide. *India Today* reported that the head of the department of plastic and reconstructive surgery at Max Healthcare in Delhi did a study of 600 patients between 2004 and 2007 which showed that the ration of male to female patients went from 25% in 2004 to 30 per cent in 2010. According to more recent journalistic reports,⁶ the ration of female to male cosmic surgery around the turn of the century was 90:1-, but now it has become 75:25 and is expected to reach 60:40. It is predicted that male breast reduction, liposuction, laser hair removal will be much more popular amongst young men, while hair transplant surgery and facelift surgery will be more popular amongst older men. The number of men having such treatments has increased by 80% since 1992.

Conclusion

At the least, we must understand that regional and local constructions of hegemonic masculinity are shaped by the articulation of these gender systems with global processes (CONNELL and MESSERSCHMIDT, 2005: 849).

Can one speak coherently of a “hegemonic body ideal” in India? And if so, can one account for how it came to be hegemonic, or how it changes? In the previous pages I have tried to suggest

⁶ <http://despardes.com/?p=11584>, Cosmetic Surgery Trends in India in 2010.

how very diverse are the “body ideals” to be found in Indian civilization. I have also shown that in recent years, a new ideal has become quite visible, invading the public sphere with its Bollywood movies, television advertising, and other new media forms.⁷ But I would not be so simplistic as to say that a group of media moguls has successfully altered the body ideals of an entire generation of Indians. Notions of what constitutes an ideal or healthy male body have been changing rapidly in India over the past twenty years, along with practices having to do with diet, exercise, dress, grooming, sex, etc., and these changes have multiple and reinforcing causes that are economic, cultural, and political at the same time.

The government of Rajiv Gandhi liberalized the Indian economy in the 1980s, and most successor governments have continued to do so. Market liberalization began with the curtailing of the so-called “License Raj”, a system of government controls that is often asserted to have inhibited Indian growth during the Nehru years. The Gandhi/ Nehru ethic of ascetic self-sacrifice for the good of society which had arisen during the independence struggle began to unravel, and was replaced by a consumerist lifestyle that fit well with the newly-unfettered economy. For the first time in a long while, one could consume luxury goods and still be a good Indian; indeed, many of the most successful new consumer products appealed precisely to Indian traditions by selling goods in the style of “ethnic chic.” This consumer ethic was radically new in that it “refuse(d) the distinction between sensual pleasure and historical progress; it made the former a necessary condition of the latter” (MAZARELLA, 2003: 141) Meanwhile India had defeated Pakistan in a series of wars and successfully tested an atomic bomb, and was demanding a seat at the table of major world powers. In the first decade of the 21st century, Indian economic growth was very impressive, and the result of all this economic, political, and military success was a burgeoning confidence amongst many middle-class Indians, summarized in the political campaign slogan “India shining.” These multiple causal factors

⁷ Compare Walle (2004), who argues that despite superficial changes, Pakistani Male basic structures of sexuality unaltered.

continue to reinforce each other, so that the new consumerist ethic shows little sign of abating. One of its correlates is the male body ideal that I have described.

But is this ideal “hegemonic”? One thing is clear: in the television advertisements, the male body has been gradually separated from a holistic nexus involving discipline, self-sacrifice, and morality, and is increasingly treated as a purely material object. Writers like Jit Singh Uberoi and Bruno Latour have said that one crucial aspect of modernity is that it separates fact from value, nature from culture. Latour calls this the “work of purification” and it can be seen in many realms: in the response of psychologists and psychiatrists to semen-loss anxiety, which is to naturalize it, remove it from the realm of morality, and firmly place it in the realm of the body; in the shift from wrestling, with its holistic discipline, to bodybuilding with its purely somatic focus; and in the change of the subject of advertising images, from a socially integrated family man to an eroticized, individualized consumer. Only time will tell if the body image associated with this kind of lifestyle will become hegemonic or not.

References

- ALTER, Joseph S. (1992) *The Wrestler's Body: Identity and Ideology in North India*. Berkeley; Los Angeles: Oxford: University of California Press.
- BEHNKE, Cornelia und MEUSER, Michael (1998) “Tausendundeine Männlichkeit? Männlichkeitsmuster und sozialstrukturelle Einbindungen”, *Widersprüche* 18: 7-25.
- BOTTERO, Alain (1991) “Consumption by semen loss in India and elsewhere”, *Culture, Medicine and Psychiatry* 15(3) 303-320.
- CONNELL, Raewyni W. and MESSERSCHMIDT James W. (2005) “Hegemonic Masculinity: Rethinking the Concept”, *Gender & Society* 19 (6) 829-859.
- DANGOR, Kimi, KRISHNAMURTHY, Akhila, VAISH, Nandini, SEN, Swagata, VINAYAK, Ramesh, MAHURKAR, Uday and DAVID Stephen (2007) “Craze for Abs”, *India Today* (last accessed on 20 October

- 2010 at <http://www.naachgaana.com/2007/10/07/craze-for-abs-india-today-cover-story/>).
- HABERMAN, David (1988) *Acting as a way of salvation: a study of raganuga bhakti sadhana*. New York: Oxford University Press.
- HEESTERMAN, Jan (1985) *The Inner Conflict of Tradition: Essays in Indian Ritual, Kingship, and Society*. Chicago: The University of Chicago Press.
- KAUR, Gagandeep (2010) "Men Get Gorgeous", Boloji.Com. (<http://www.boloji.com/wfs5/wfs984.htm>, accessed on 25 April 2010).
- MALHOTRA, H. K. and N.N. WHIG (1975) "Dhat Syndrome: A Culture-Bound Sex Neurosis of the Orient", *Archives of Sexual Behavior* 4 (5): 519-28.
- MARRIOTT, McKim (1976) "Hindu Transactions: Diversity Without Dualism", in KAPFERER, Bruce (ed.) *Transaction and Meaning*, pp. 109-42. Philadelphia: ISHI.
- MAZZARELLA, William (2003) *Shoveling Smoke: Advertising and Globalization in Contemporary India*. Durham and London: Duke University Press.
- MILLER, Barbara Stoller (1977) *Love Song of the Dark Lord: Jayadeva's Gitagovinda*. New York: Columbia University Press.
- MUMFORD, David B. (1996) "The 'Dhat syndrome': a culturally determined symptom of depression?" *Acta Psychiatrica Scandinavica* 94: 163-67.
- NADKARNI, K. M. (1954) 1994. *Dr. K. M. Nadkarni's Indian Materia Medica. With Ayurvedic, Unani-Tibbi, Siddha, Allopathic, Homeopathic, Naturopathic & Home Remedies, Appendices & indexes*. 2 Vols. Revised & Enlarged by A. K. Nadkarni. 3rd edition 1954, Reprint 1994. Bombay: Popular Prakashan.
- PARIS, Joel (1992) "Dhat: The Semen Loss Anxiety Syndrome", *Transcultural Psychiatry* 29: 109-118.
- SAX, William S. (2006) "Rituals of the Warrior *kbund*", in SAX, William S. (ed.) *European Bulletin of Himalayan Research* 29-30: 120-134.
- SHARMA, Priya Vrat (1981-1998) *Dravyaguna-Vijñāna*. 5 Vols. Varanasi: Chaukhambha Bharati Academy. (V. Ayurveda Series 3).

WALLE, Thomas Michael (2004) "Virginity vs. decency: continuity and change in Pakistani men's perception of sexuality and women," In OSELLA, C. & F. OSELLA (eds), *South Asian Masculinities*. Delhi: Kali for Women/Women's Unlimited Press.

ASYMPTOMATIC CHOLESTEROL, “WONDERDRUGS” AND WESTERN FORMS OF PHARMACEUTICAL INCLUSION

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Introduction: cholesterol as both natural and cultural

Nowadays everybody is talking about “their” cholesterol, whether it is good or bad and how it influences their food preferences. How is it that we are all so blithely discussing cholesterol, a substance so far removed from the routines of daily life? Cholesterol is no longer the nondescript and silent body worker engaged in numerous essential biochemical processes, such as the synthesis of sexual hormones! It is now a hot topic of conversation and has become a biomedical icon of Western culture, one which spawns strong opinions and even fuels long lasting controversies. Indeed, cholesterol has emerged in Western societies as an object of both scientific and common knowledge.

Not only do we talk about cholesterol, we also feel compelled to monitor and treat it. To reduce cholesterol levels, we turn to the family of statin drugs, invented in the late 1970s, first marketed in the 1980s and now used world wide, especially in Western countries. At the turn of this century, we saw the rise of a massive statin consumption. Statin prescriptions rose by more than 30% per year from 1998 to 2002 in Europe (WALLEY *et alii*, 2004). Lipitor®, Pfizer’s blockbuster, is the worlds best selling drug and statin drugs in general were the best selling therapeutic class in the US in 2006 and 2007 (raking in more than 15 billions dollars a year in sales (IMS, 2007). Although patents do expire, these drugs – whether generics or patented – are still being marketed with new indications. Such drugs eventually become consumer

items as well as modern icons. They now seem to shape the way we express our health concerns to an even greater extent, what we do to alleviate them.

Molecularization of the living, on which statin development is based, for instance, has been characterized as part of the very “politics of life itself” (ROSE, 2007). In this same perspective, Clarke (CLARKE *et alii*, 2003) has made another interesting breakthrough with the concept of “Biomedicalization”. Drawing on the technoscientific transformations of biomedicine and the resulting production, distribution and consumption of biomedical knowledge, Clarke uses this concept to analyse the transformation of bodies and identities. Such concepts can help to grasp and understand the rapidly evolving ways biotechnologies such as drugs are being used in the neo-liberal era and how they contribute to transformation of society. How is the global use of statin drugs symptomatic of this global shift of control from welfare-state legislation and programs to neo-liberal governance and how does it fit in with and inform existing models of social identity making?

The noisy new global discourse about of cholesterol and its treatment contrast with the silent local body processes in which this sterol is involved – processes that are most of the time asymptomatic. It is common knowledge that psychotropic pharmaceuticals contribute to the definition of psychiatric disorders (HEALY, 2004; COLLIN, 2005; LAKOFF, 2005). The constructivist ontology of the diagnosis of mental disorders and their therapeutics derived from a science studies’ framework is gaining more and more ground. Cholesterol therapeutics intervention are raising new issues and spreading this view based on body’s materiality, precisely because cholesterol is *real* and deeply rooted in the body. Given that cholesterol is *real* and *historical*, this should make it easier to avoid the pitfalls inherent in realist/relativist debates. It should also help us configure objects and subjects that are shaped both by therapeutic and political power. The pharmaceutical inclusions or exclusions resulting from this process are precisely at the crossroads of the scientific practice of making objects and the recognition of social and economical capacity of subjects.

A genealogy of the statin drugs – from their production to their availability and use – reveals the economic and political networks in which such “wonderdrugs” are embedded. Taking a historical look at cholesterol, from its first appearance on the scientific scene to the discovery of its properties in the twentieth century – will help us understand how it is being used in the socio-political context to transform social time and space through the very ways in which we perceive our body and relate to it –. A comparison of policies and practices in the US, the UK and France will let us contrast various ways of appropriating drugs and help us see how asymptomatic conditions and their treatment are socially shaped and politically controlled. We will first give a short account of cholesterol’s scientific biography and explore the pathways from its transformation into an asymptomatic risk factor to the rise of statins as “wonderdrugs”. And, finally we shall analyze the varying access to those drugs and their emergence as a biopolitical issue.

A short biography of cholesterol

How is it that cholesterol has emerged as such a real and normal object that it has even acquired moral over tones? Drawing on Lorraine Daston’s concept of the “biography of scientific object” (DASTON, 2000) we shall try to follow cholesterol as both a real and historical object. Three moments are key to cholesterol’s biography: its emergence, productivity and its embeddedness.

EMERGENCE

Of course we know that even before cholesterol was so named it was already at work in human bodies. As we shall see, what is so remarkable when following the trace of a scientific object such as cholesterol is that how its properties and its salience in society will depend very much on the way the “community of thought” (FLECK, 1981) has not only discovered it but also invented it. In the case of cholesterol we shall briefly explore how, thanks to the

scientific inquiry, cholesterol has come into being as a scientific object, albeit not one created *ex nihilo*.

Poullétier de la Salle might have been the first to take an interest in cholesterol. It was he, in the 18th century, isolated its crystals from biliary acids. But despite this favourable outcome of his aristocratic curiosity, no name was then given to the compound isolated but not put to any use. In the early 19th century, chemist Chevreul gave the name “cholesterine” to the substance he extracted and identified from biliary stones. Chevreul, already well recognized at the time, is in deed, credited with having customized the saponification process which he used to obtain the unsaponifiable substances such as cholesterine, and stearic acid (patented to renew candels at that time) as well as major alkaloids, thus playing an important role in the development of medical-research practices (FOURNIER, 2001). Cholesterol is hence rooted in the rise of chemistry in the 19th century. At the beginning of the 20th century the name cholesterol spread in scientific literature written in English. The substance was, however, not studied and its chemical structure and properties were yet to be specified.

While working on a systematic description of lipoproteins in the 1920's, the French chemist Marcheboeuf isolated and identified the blood soluble lipoproteins contained in horse serum, which are now recognized as High Density Lipoproteins (HDL). Cholesterol began to take its place in the classification of lipoproteins and was then attributed observed and expected properties. A few years earlier, in 1913, Anitckow had observed cholesterol's first physiological property, establishing the relation between cholesterol and atherosclerosis in the rabbit.

What is now called cholesterol existed long before it was named, but it was soon to be redefined or reinvented thanks to the inventive lenses of human curiosity, observation, and classification permitted by the social context of that time. New tools and techniques that were becoming available at that time also helped its specification and emergence in the scientific community. As a scientific object it has also produced noteworthy advances in scientific knowledge and practices.

PRODUCTIVITY

Cholesterol has produced various sorts of objects and practices: from advances in basic research to new social practices. In 1927, Wieland received the Nobel Prize for his work on the description of lipoproteins; in 1985, Brown and Goldstein were awarded the same prize for their research on the regulations of cholesterol metabolism. In between, many other Nobel Prizes were awarded in the web of cholesterol¹. Cholesterol's scientific history has been glorious and well publicized; this has been one of the beachheads for its penetration into social networks.

In the 1960's, cholesterol produced also various types of social outcomes. For instance, after Ancel Keys took cholesterol out of the lab and put it in the spotlight of American news media, dietary concerns soon featured prominently on the public health's agendas. After major controversies, food industry agreed to include cholesterol content on its products labeling: "good cholesterol", "bad cholesterol" and "cholesterol free" were soon to appear on food labels in all Western supermarkets. On the other side of these growing dietary concerns, cholesterol also produced strong expectations about some kind of anti-cholesterol treatment -a magic bullet-. And ever since the early 1960s there have been more or less successful attempts to develop cholesterol-lowering drugs². The manner in which Akiro Endo discovered statins mirrors the way many researchers of the day perceived the cholesterol phenomenon and reacted to it. Once cholesterol had been named and identified, the war metaphor imported from the germ theory

¹ Prizes among which: Windaus, 1928; Butenandt and Ruzicka, 1939; Robinson 1947, Diels and Adler, 1950; Bloch and Lynen in 1964 for their research on metabolism regulation of cholesterol and fatty acids; Woodward in 1965 for the practical breakthrough with the synthesis of cholesterol based protein such as cortisol.

² The Food and Drug Administration withdrew Triparanol (marketed in the US in 1959) from the market for major toxicity in 1962. This drug completely blocks cholestérol synthesis is also representative of a specific medical reasoning about cholesterol as an invader and somehow something to be eradicated. Clofibrate, has then been developped in 1962 and other durgs of this class are still used nowadays such as fénofibrate.

could be applied to this newly designated public enemy. Thought turned to Fleming's accidental discovery of penicillin and soon thousands of yeasts were being tested to find cholesterol's penicillin. That's the path to Endo's success! He found a specific type of yeast producing an inhibitor of an enzyme called HMG CoA which is essential to the synthesis of cholesterol. Toxicity and efficacy profiles observed in clinical trials later confirmed this breakthrough.

Cholesterol has been productive in the sense that it has provoked the emergence of new scientific objects, as well as social concerns and trend. A new labeling of things and subjects through the cholesterol scope prompted people to wake up and do things: coverage in the news media, stimulation of medical research, change in eating habits etc... The way cholesterol has been discovered *and* invented is a prime example of "making make" and "making do".

EMBEDDEDNESS

This short history hints at how reality of cholesterol depends fundamentally and methodologically on the specific networks of human and non-human actors in and by which it has been (and is being) constructed. Cholesterol's rudimentary chemical formula ($C_{27}H_{46}O$) was worked out in 1890 but its more exact version was produced only in the 1930s. In between chemists had worked intensively on cholesterol structure, dozens of labs were mobilized in Germany, France, the US and the UK, devices such as crystallography and the X rays were called into service; quality procedures were used to support the web of equipment, devices, people, organizations, and institutes that kept the cholesterol phenomenon going. Since its biochemical components were spelled out in the 1930's, cholesterol has starred in variable and concurrent networks. First, it played an important role in large epidemiological studies such as the Framingham study in the late 1940's. Second, its role as an health concern was played out in local, material and practical network that would support cholesterol's social status. Third, ever since the 1950s, specific networks – such as those in the drug development industry – had

also been trying hard to enmesh cholesterol in their web, though only more or less successfully, until the advent of statin drugs.

Based on this short biography we see that cholesterol, as a scientific object, has become embedded in the broad social and political context in which it was produced. And it is this context which determines the way scientific and social networks are defining their object through power relations that depend on the density of facts sustaining them. Cholesterol evolves in conjunction with the density of facts to which it is connected. The inscription of cholesterol into wider networks of material practices, cultural significance and theoretical derivation has surely helped to make this sterol what it now is – not only a scientific object but also a dynamic ordinary object of everyday life –. We shall next describe how, at the beginning of the xxist century, cholesterol, statin drugs and their attendant social practices have now become embedded.

*From the asymptomatic risk factor to the rise
of a global intervention through “wonderdrugs”*

THE MAKING OF CHOLESTEROL RISK AND ITS CONCOMITANT CONTROVERSIES

After World War II, new forms of governing life through collective management of health and social welfare appeared in Western countries. These were mostly based on: *i*) universal health insurance for major segments of the population (through work, income taxes or private insurance), *ii*) major investments in health research and drug therapies and *iii*) attempts to evaluate and reduce risk. The transition from risk management to its evaluation in epidemiological studies such as the blood pressure study in 1939 and the Framingham study in 1947 was very quick (ROTHSTEIN, 2003). Insurance companies were likely to pay for such studies. As a matter of fact, screening for cardio-vascular risk is a product of insurance companies' will to know, as was temperature monitoring in German hospitals in the 1930s (GAUDILLIÈRE, 2006). The two main consequences of this biopolitics of risk were: *i*) the individualization of social medicine problems and *ii*) the use of

statistics as political tools to produce controversies or consensus in a field where lobbies work hard to defend their market share.

Up to the late 1960's, as there was as yet no effective medical treatment for cholesterol, many physicians still agreed that dietary changes favoring low-cholesterol food would be safer and more effective. Other physicians, such as those affiliated with the American Heart Association, questioned the efficacy of low cholesterol diets, seeing them as a potential threat to their medical authority (GARRETY, 1997). It was controversies like these – supported by the various networks defining cholesterol and its relations to diet and disease – that were the practical means by which cholesterol continued its penetration into people's everyday life. Broad controversies as to just how "guilty" cholesterol really was lasted until the 1990's, until notions about good and bad cholesterol were more commonly known among Western consumers. But these controversies also reveal the unsteadiness of cholesterol's embeddedness. No final proof of its effects had yet been accepted and punctual proofs were being used to falsify any systematic theory. However, the discovery of statins and their use would change this situation³.

Pharmaceutical embeddedness and the end of cholesterol controversies:

As facts linking cholesterol and statin drugs multiplied and intensified in the 1990's, cholesterol became strongly associated with this particular network. More precisely the work for which Michael Brown and Joseph Goldstein were awarded a Nobel Prize marked a turning point. Their research on the genetic basis for high cholesterol in some patients elucidated the mechanism for LDL disposal by the liver. Their findings – which directly echoed the results of the Lipid Research Clinic Coronary Primary Prevention Trial (LRCCPPT) published in the JAMA in 1984 (LIPID RESEARCH CLINIC PROGRAM, 1984) – served to bring about a sea

³ See our previous work (DAVID, forthcoming) describing the evolution of thematic intensity between "cholesterol", "diet" and "risk" in American news media. Since statin drugs have been marketed, cholesterol is more related to risk than diet in the US in the scientific press, the daily press and the magazine press.

change in attitudes towards pharmacologic means of lowering LDL cholesterol. These means are subsequently to be accepted as a definite help in reducing coronary heart disease. The synergy of these events helped to launch the first statin on the US market in 1987: lovastatin, Merck's Mevacor®. As a result, the network of relations between cholesterol and statin drugs was even stronger and would continue to be regularly reinforced by clinical trial data.

Daniel Steinberg's articles (2006) entitled "cholesterol wars": *statins and the end of cholesterol controversy* reviews the history of cholesterol controversies and asserts univocally that the advent of statins has settled them. Steinberg has spent more than 40 years on lipid research. He has worked for Merck's pharmaceutical industry in the US and, more precisely, for the development of lovastatin. When wrapping up his review of the cholesterol wars, Steinberg presents an interesting mix of enthusiastic account of clinical trials, their results, and great expectations about what he calls "wonderdrugs" and their broader use⁴. In this scientific and industry oriented vision, (and thanks to the web of consensus and connections spun by cholesterol facts) statin drugs are ready for use in performative narratives designed to shape a potential future based on so-called technologies of hope (LEIBNIG and TOURNAY, 2010).

NORMALITY AND NORMALIZATION

Clinical trials for statin drugs are now redefining cholesterol's abnormal and pathological levels (GREENE, 2007). With every drop in cholesterol's pathological threshold, more of the normal population becomes abnormal. Recommendations and guidelines for cholesterol levels (according cardiovascular risks) expand such

⁴ These expectations about statin drugs are not only those of Steinberg but of a large part of the researchers proposing to extend the use of statins whether to old patients as those drugs might prevent Alzheimer (KIVILPELTO *et alii*, 2006) as well as for kids! (the latest recommendations from the American Academy of Pediatrics (AAP) to widen cholesterol-testing to include kids as young as two raises the question of statin use for them as debated in press magazine such a Time magazine "the kiddie cholesterol debate", 2008).

a process. As is clearly evident in Steinberg's discourse, there is no lower limit for low density cholesterol (LDL) reduction. Specific clinical trials have shown that as the LDL level drops so does mortality rate: so, the lower the better! Drugs are thus turned into tools for *customizing* bodies whether: normal or pathological. On the flip side of this coin, drugs change the standards for risk levels as well as the way individuals interpret and relate to the normal/pathological condition of their own bodies. This amounts to a new rationalization of cholesterol as pathogen, a socially constructed rationalization rooted in the concrete possibility of transforming bodies that show no signs of disease. A normalization process based on the therapeutic power is hence shaping a culturally customized biological normality.

Aronowitz calls our attention on the paradoxical aspects of an approach which would merge diseases with risk factors, and he points out three aspects that are particularly enlightening in the case of cholesterol (ARONOWITZ, 1999). First, the social distribution of myocardial infarction contravenes attempts to individualize risk by making a matter of personal responsibility. Second, holist knowledge has thoroughly integrated the molecular interpretation of the disease and, third, the promotion of prevention based on education and behavior has ended with a massive prescription of drugs. The diffusion of objects such as statins is a global response to scientific risk speak rather than to symptomatic conditions rooted in the body. What are the consequences for individuals and citizens of this shifting frontier between the normal and the pathological? This question brings us to the issue of access to statin drugs and their practical use.

Access problems and Western forms of pharmaceutical inclusion

There are at least three major reasons why access to statin drugs can be analyzed as a biopolitical issue. First, statin drugs have appeared on the scene as a therapeutic strategy which derive its power not only from intrinsic specificities but also from the definition of cholesterol as a risk factor. Secondly, in the countries with a welfare system, access to drugs is determined by the state

and its rationalities (cost-effectiveness assessments, industry oriented perspective, patients' perspective...), this collective management of health constitutes what has been conceptualized as "life government" (FASSIN, 1996). Third, pressures put on the whole health system by statins and their increasing cost have prompted a shift from collective to individual health insurance coverage and has made statins accessible as over the counter (OTC) rather than prescription drugs. This shift in access is deeply related to the transfer of responsibility from the collectivity to individuals. Let's now take a brief look at how statin drugs access has been managed in three different countries: the United Kingdom, France, and the United States of America.

In 2004, the United Kingdom's National Health System (NHS) switched simvastatine 10 mg (also known as Zocor®) to OTC status. From a medical perspective, this move has been considered very controversial: "bad decision for public health" states the heading of a Lancet editorial. And from a sociological perspective, Edgley and Abraham have wondered whether the switch was an industry or administrative oriented decision (ABRAHAM, 2007). A 2008 study concluded that the OTC availability of statins did not appear to be considered a popular public health intervention among consumers and health professionals, as the drugs were widely perceived as being "prone to misuse". However, "OTC availability was favored by pharmacists, who saw this as empowering both for consumers and themselves. Key issues in dispensing, managing, and evaluating the public health impact of this intervention remain outstanding" (VAMVAKOPOULOS *et alii*, 2008).

For France's Assurance Maladie, statin drugs have been a source of wonder and worry ever since they began to head the list of reimbursable drugs. This worry was actualized by what has been called a "consumption phenomena", an expression rarely used for prescription drugs in France. The findings of a public consultation held by the Haute Autorité de Santé (HAS) were published in November 2009: "efficacité et efficience des statines: critère: coût/efficacité biologique". After examining the use of each statin drug, the key question became: what is the target population? The answer was that cardiovascular risk should be considered but not initial pathology. This would lead to issues

concerning the threshold(s) of cardiovascular risk. As its final recommendation, the report proposes that the population should be classified into three groups as regards cardiovascular risk (low, intermediate, high) so as to determine relative risk levels and adapt therapeutic treatment accordingly.

In the United States of America, the moving limit between normal and pathological has showed how clinical trials have contributed to the transfer of the statistically “normal” population to a mostly pathological population requiring therapy. Direct and indirect advertisements addressed to the patients are common fare in the US. But pharmaceutical industry is now exerting stronger pressure on the Food and Drug Administration to have their statins switched from prescription to OTC status. Three formal requests have already, *so far* unsuccessfully (TINETTI, 2008). In february 2010, the FDA accepted the use of Crestor® as a primary preventative treatment for cardiovascular diseases. This new therapeutic prevention reasoning is based on an inflammation indicator called Reactive C-protein whose specific link to cardiovascular risk is still quite unclear (LLOYD-JONES *et alii*, 2006). OTC delivery models have proven to be ineffective for the time being (BRASS *et alii*, 2006), but for how much longer?

These three contrasting examples give us some idea of today's global rationality concerning statins as well as how their use may be defined in a specific local and political context. Targeting specific populations is one of the major consequences of life government and its therapeutic power. By determining cardiovascular risk thresholds, science constructs specific categories that can be used to screen the population and to act upon it. Then, too, there is the individualizing power of drugs: First, in the additional institutional resources allotted to individuals and, secondly, in the way the individuals are induced to transform themselves through the very transformation of their “proper” body. In this sense, switching statin from prescription to OTC status is also symptomatic of the global shift from welfare-state subjects to liberal individuals, thanks to a global assemblage of cost-effectiveness analyses, moving risk thresholds and drug therapies.

The link between “public health space” and the construction of social identity (ARMSTRONG, 1993) needs to be explored now that

easier access to statin drugs extends the “sanitary cordon” not only to pharmacies but also into private lives. By its retreat the state is clearly presuming upon people’s informational and economical capacities, thus reinforcing these new forms of subjectification. This process linking therapeutic power to subjectification results in political forms of pharmaceutical inclusion. Though less radically than do hormones or reproductive technologies, statins do transform the body and its risk levels, both cardiovascular and hepatic (one of statins’ side effect). Transforming the asymptomatic body is also a means of constructing a socially correct self-image and of adapting to modernity’s health and performance values. This therapeutic “souci de soi” (FOUCAULT, 1984) is evidence of how subjects are being produced by new patterns of consumption and by the subjectification of risk categories through managed access to therapeutics.

The question concerning the role of time in this transformation of the body remains: are we looking at ephemeral changes or at real in depth transformations that will create new temporalities and spacings in the context of endless treatment. In either case, these transformations of the body (perhaps cosmetic at first) depend on transformations of subjectivity (observance, temporality and continuity in drug use), which will, in the end, change risk for the “pharmaceutically included”. In this context, drugs are used to widen a political health-space governed by biopolitics of risks. If the use of statin drugs can be seen as a practice spaced in the global liberal era, it can also be seen as a spacing practice – spacing both the body and the social milieu by affecting the self as well as the body. Such practices change our social reality through the very transformation of our bodies whose commodification – and not just modification – appears as more and more deeply linked to a neo-liberal subjectivity.

Conclusion: rethinking the loop

The history of cholesterol and its treatment provides a prime and significant example of the loop linking social and biological phenomena: its discovery and naming as a scientific object,

its career as an invention of scientific research, its appearance as a risk factor in post-war public health policies, reactions to its risk-factor status such as dietary concerns or the use of pharmaceuticals such as statins. Such phenomena are shaped by the broader social context which determines how cultural values will exert their influence. In the neo-liberal era, the growth and spread of statin use raises the issue of access to these drugs by which the self may be refashioned and the body transformed: “making up numbers” can deeply influence not only how drugs are prescribed but also how they serve to make up those who, drawn into their therapeutic net, use them to take care of their “sacred selves” and (knowingly or not) to transform their bodies. This particular approach to care of the self might be symptomatic of the socio-economic inequalities reproduction haunting both the Western self and Western societies which are then introjected into bodies, inasmuch as cardiovascular risk will be lowered for those bodies which are included.

Another less critical conclusion would be to point out the deep connection between science and democracy results in a social process of identity making. In this process, citizens, as both producer and consumer of knowledge, exercise their economical power in a manner organizing normalized consumption patterns and promoting normative ends. Pharmaceutical inclusion then appears to be the outcome of a whole scientific and political process. There are some, indeed, “political moments” but they do not always occur where we would expect them to take place, such as in the National Assembly or in the course of a democratic election. Some of such moments may occur in places where health and drugs agencies make their decisions about how drugs are designed or distributed: Such decisions are also forms of political inclusion or exclusion.

The global loop from cholesterol numbers to pharmaceutical inclusion can help inform local ethnographies that demonstrate the way people appropriate these self-technologies and adapt them to the local social context in which they live and to the patterns of modernity they imagine. Local ethnographies could indeed be used to document: *i)* the way physicians apply guidelines and practice Evidence Based Medicine and hence face and produce

vulnerability, *ii*) the way people take their pills and adhere to medical recommendations, and *iii*) the way they change their lifestyles by means of self diagnosis, self monitoring and perhaps alternative health strategies. On this basis a comparison between Western countries could be made so as to specify local forms of global health. In the end, Dagognet's question still remains (DAGOGNET, 1964): are remedies overcoming reason? As applied to statin drugs, the answer might be: though they are remedies based on and promoting a global rationale, their uses just might reveal local reasonableness.

References

- ABRAHAM, John (2007) "From Evidence to Theory: Neo-Liberal Corporate Bias as a Framework for Understanding UK Pharmaceuticals Regulation – Response to Alison Edgley", *Social Theory & Health*, 5(2), 161-175. doi:10.1057/palgrave.sth.8700097.
- ARMSTRONG, David (1993) "Public Health Spaces and the Fabrication of Identity", *Sociology*, 27(3), 393-410. doi:10.1177/0038038593027003004.
- ARONOWITZ, Robert A. (1999) *Making sense of illness: science, society, and disease*. Cambridge: University Press.
- BRASS, Eric P., ALLEN, Shannon. E., & MELIN, Jeffrey M. (2006). "Potential Impact on Cardiovascular Public Health of Over-the-Counter Statin Availability". *The American Journal of Cardiology*, 97(6), 851-856. doi:10.1016/j.amjcard.2005.10.022
- CLARKE, Adele E., SHIM, Janet K., MAMO, Laura., FOSKET, Jennifer R., & FISHMAN, Jennifer R. (2003) "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine", *American Sociological Review* 68(2), 161-194.
- COLLIN, Johanne (2005) "Médicaments psychotropes: quelques mythes à détruire", *Cahiers de recherche sociologique* 41-42; 115-134.
- DAGOGNET, François (1964) *La raison et les remèdes*. Paris: Presses universitaires de France.

- DASTON, Lorraine (2000) *Biographies of scientific objects*. Chicago: University of Chicago Press.
- DASTON, Lorraine & GALISON, Peter (2010) *Objectivity*. New York: Zone Books.
- DAVID, Pierre-Marie (forthcoming) «Statines et reconfiguration de la médicalisation liée au cholestérol dans les sociétés occidentales», *Socio-logos*.
- FASSIN, Didier (1996). *L'espace politique de la santé: essai de généalogie*. Paris: Presses universitaires de France.
- FLECK, Ludwig & TRENN, Thaddeus J. (1981) *Genesis and development of a scientific fact*. Chicago: University of Chicago Press.
- FOUCAULT, Michel (1984). *Le souci de soi*. Paris: Gallimard.
- FOURNIER, Josette (2001) "Découverte des alcaloïdes. Des marqueurs pour l'histoire de la chimie organique". *Revue d'histoire de la pharmacie* 89(331), 315-332. doi:10.3406/pharm.2001.5245
- GARRETY, Karin (1997) "Social Worlds, Actor-Networks and Controversy: The Case of Cholesterol, Dietary Fat and Heart Disease". *Social Studies of Science* 27(5), 727-773.
- GAUDILLIÈRE, Jean-Paul (2006) *La médecine et les sciences: XIXe-XXe siècles*. Paris: La Découverte.
- GREENE, Jeremy (2007) *Prescribing by numbers: drugs and the definition of disease*. Baltimore: Johns Hopkins University Press.
- HAS HAUTE AUTORITÉ DE SANTÉ: "Efficacité et efficience des statines : critère: coût/efficacité biologique" published in November 2009.
- HEALY, David (2004) *The Creation of Psychopharmacology*. Harvard: Harvard University Press.
- IMS Health (2007) US sales and prescription information. www.imshealth.com/ims/portal/front/~. Accessed on november 2008, the 15th.
- KIVIPELTO, Miia, SOLOMON, Alina, BLENNOW, Kaj., OLSSON, Annika G. & WINBLAD, Bengt (2006) "The new cholesterol controversy – a little bit of history repeating?" *Acta Neurologica Scandinavica. Supplementum*, 185, 1-2. doi:10.1111/j.1600-0404.2006.00678.x

- LAKOFF, Andrew (2005) *Pharmaceutical reason: knowledge and value in global psychiatry*. Cambridge: Cambridge University Press.
- LEIBING, Annette, TOURNAY, Virginie (2010) *Les technologies de l'espoir. La fabrique d'une histoire à accomplir* – Quebec: Les Presses de l'Université Laval. Retrieved August 19, 2010, from <http://www.pulaval.com/catalogue/les-technologies-espoir-fabrique-une-histoire-9504.html>.
- LIPID RESEARCH CLINICS PROGRAM (1984) "The Lipid Research Clinics Coronary Primary Prevention Trial Results: II. The Relationship of Reduction in Incidence of Coronary Heart Disease to Cholesterol Lowering" *JAMA* 251(3) 365-374. doi:10.1001/jama.1984.03340270043026.
- LLOYD-JONES, Donald M., LIU, KIANG, TIAN, Lu & GREENLAND, Philip (2006) "Narrative Review: Assessment of C-Reactive Protein in Risk Prediction for Cardiovascular Disease" *Annals of Internal Medicine* 145(1) 35-42.
- OLSON, Robert E. (1998) "Discovery of the Lipoproteins, Their Role in Fat Transport and Their Significance as Risk Factors" *J. Nutr.* 128(2) 439S.
- ROSE, Nikolas S. (2007) *The politics of life itself: biomedicine, power, and subjectivity in the twenty-first century*. Princeton: Princeton University Press.
- ROTHSTEIN, William G. (2003) *Public health and the risk factor: a history of an uneven medical revolution*. New York: University of Rochester Press.
- STEINBERG, Daniel (2006) "An interpretative history of the cholesterol controversy part V: the discovery of statins and the end of the controversy" *Journ of Lipid research* 47 1339-1351.
- TINETTI, Mary E. (2008) "Over-the-counter sales of statins and other drugs for asymptomatic conditions." *N Engl J Med* 358(25) 2728-2732.
- VAMVAKOPOULOS, Joannis E., KOUNTOURI, Melpomeni, MARSHALL, Tom & GREENFIELD, Sheila M. (2008) "Lifestyle or Life-Saving Medicines? A Primary Healthcare Professional and Consumer Opinion Survey on Over-the-Counter Statins" *Ann Pharmacother* 42(3) 413-420. doi:10.1345/aph.1K421.

WALLEY, Tom, FOLINO-GALLO, Pietro, SCHWABE, Ulrich & Van GANSE, Eric (2004) "Variations and increase in use of statins across Europe: data from administrative databases" *BMJ* 328(7436) 385-386. doi:10.1136/bmj.328.7436.385.

REDEFINING THE BOUNDARIES OF HUMANITY. THE CASE OF ALLO- AND XENOTRANSPLANTATION

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In the 1960s, after decades of fruitless attempts, organ transplantation between humans (allotransplantation) became a therapeutic reality. Today it is standard practice in ordinary medicine, to the extent that a new problem has arisen: the shortage of organs. As the constant improvement of the therapy has made it possible to graft increasing numbers of patients, including the most elderly and the most fragile, a new population has emerged: “patients waiting for a graft”. In 2008, in France, there were 13,698 individuals in this category, 424 of whom died during the year¹. To remedy this situation, alternative sources of grafts have been envisaged. Xenotransplantation, the use of animals for grafting humans, has been promoted as a possible solution to the shortage (GODBOUT, 2009). It is seen as a way to multiply the number of available organs and to eliminate the commodification of human grafts, thus avoiding the ethical issues associated with such practices.

Xenotransplantation is sometimes presented as an unprecedented innovation. Yet it is by no means an invention of the 21st century stemming from the shortage of organs, nor an absurd extension of grafting spawned by the imagination of adventurous scientists. On the contrary, it was originally the first solution envisaged for organ transplantation. As such, it was couched in the tradition of experimental medicine which sought to substitute animals for humans in ways that were ethically highly

¹ Agence de la Biomédecine Report, 2008.

problematical. With the invention of the concept of transplantation at the end of the 19th century, surgeons initially turned to animal bodies for organs, because of their availability (SCHLICH, 1997). Despite recurrent failures, numerous xenograft trials were carried out during the 20th century. Thus, the idea of grafting an animal organ on a human being is as old as the very idea of transplanting organs. As animals could be used without any problem, they were initially seen as the best sources of grafts.

Although they share a common history in some respects, allotransplantation and xenotransplantation appear to be so radically different that they have rarely been treated together in the organ transplant literature (FOX & SWAZEY, 2002; LOCK, 2002; BROWN, 1999). This difference is obvious: organs for grafts are taken from humans, on the one hand, and from animals, on the other. More exactly, in one instance the practice consists in removing an organ from a dead human and giving it to another human, whereas in the other it consists in killing an animal to remove an organ that will then be used as a substitute for a human organ.

This is what seems to entail distinct ethical and technical problems, thus making any attempt to liken the one to the other suspect. Yet that is precisely the approach that I take in the present article. In this respect my work follows on from that of anthropologist Lesley Sharp who, envisaging transplantation as “an exotic branch of medical culture” (SHARP, 2006: 2), analyzed the status of the donor, whether human or animal, in the North American context. I also try to narrow down the gap between these two types of practice by focusing on the fact that they both bring to the fore, with great clarity, the common issue of the redefinition of the boundaries of humanity. I argue that grafting between humans and grafting between animals and humans both contribute, each in its own way, to reshaping the human category and to altering the scale of beings. And this alteration takes place less at the level of the receiver – as one might imagine, especially when it is a matter of a graft – as at that of the donor.

The question of the “boundaries of humanity” is in a sense at the heart of the anthropological project. I distinguish two ways of addressing the issue. The first is normative: the anthropologist draws a line between that which is “peculiar to humans” and that

which is not (MALINOWSKI, 1968; LÉVI-STRAUSS, 1983). The second way of considering the “boundaries of humanity” is descriptive: a form of reflection on the way in which any being can be humanized or dehumanized. From this point of view humanity appears to be the result of processes that make it either appear or disappear. This is the perspective that I adopt here. I therefore take seriously Margaret Lock’s argument that transplantation has blurred the boundaries between the living and the dead, between nature and culture (LOCK, 2002). But although this anthropologist emphasizes the importance of boundary work, she does not specifically consider the question of the definition of humans in the context of transplantation. By comparing allo- and xenotransplantation, I endeavour to show that a real “ontological upheaval” has taken place, entailing – over and above a blurring of the boundaries between the living and the dead, nature and culture – a *dehumanization* of certain humans and a *humanization* of certain non-humans.

To explore this interplay on the boundaries of humanity, which is above all an interplay on bodies, I analyze two controversies: the first, in the 1980s in the United States, was over an attempt to graft a baboon heart onto a neonate, while the second, in the 1990s in France, concerned the removal of organs from a young man who had died in a bicycle accident. In the academic literature these two controversies are presented as significant cases in the history of transplantation, even though they are usually summed up in no more than a few sentences (LEDERER, 2008: 204; SHARP, 2006: 314; WAISSMAN, 2001: 14). As the anthropology of science and techniques shows us (CALLON & LATOUR, 1991), it is important to take the controversies punctuating innovation processes seriously. Opening these “black boxes” and describing in detail the arguments exchanged enables us to understand the problems generated by these new practices – problems which, outside of these periods of debate or scandal, are usually left unsaid or implicit. Naturally, each practice has its own problems. For example, xenotransplantation begs the question of the encounter between, or even the merging of, species. In this sense this article subscribes to the project of multi-species ethnography (KIRKSEY & HELMREICH, 2010) “an anthropology that is not just confined to the

human but is concerned with the effects of our entanglements with other kinds of living selves” (KOHN, 2007: 4). In the case of xenografts, this question can be addressed in different ways. One strategy consists in examining how human recipients perceive a potential hybridization of the human body (PAPAGAROUFALI, 1996; FELLOUS, 2004; SHARP, 2006). Another – that I adopt here – is to analyze scientific practice in relation to its contradictors. This enables us to illuminate the process of narrowing or widening the gap between humans and animals which, from a technical and moral point of view, is needed to perform an inter-species graft. The second controversy examined in this paper concerns the impact of the appearance of hybrids between dead and living beings in the French context. Margaret Lock points out that in North America and Europe the transplantation of organs has become standard practice, but that in the process the ambiguities and doubts generated by such hybrids are totally disregarded. Analysing this controversy is of particular interest in that it enables us to study the effects of the *mise en visibilité* – the fact of “making visible” – that which is usually kept covert. What happens when the status of hybridity is publicly criticized by members of the donor’s family?

The “sacrifice” of Baby Fae and the baboon goobers

On 26 October 1984, at the Loma Linda hospital in California, a surgeon, Leonard Bailey, transplanted a baboon heart onto a ten-day-old baby girl. Baby Fae – as she was nicknamed – died on 15 November 1984, twenty days after the operation. This test received extensive media coverage and controversy broke out the day after the operation².

² The corpus mobilized for this analysis consisted of 179 press articles published in the United States, secondary literature on the subject, and a video documentary produced by the Loma Linda Hospital, as well as various documents available on line (<http://www.llu.edu/news/360/2009/babyfae-30min.page>).

The medical team and representatives of the hospital tried to justify the operation in the following terms: the transplant was a last resort; there was no human heart available at the time of the operation; the team had carried out experiments on animals prior to the transplant; the hospital's ethics committee had given the green light; if successful, the operation could be a source of great hope in solving the problem of the shortage of organs; the close resemblance between the human heart and the baboon's heart made the operation credible; and the sacrifice of an animal was legitimate if it was to save a human life.

This question of sacrificing an animal was actually a key issue in the controversy. The day after the operation, animal rights activists demonstrated outside the hospital, where journalists readily served as their spokespersons. The activists argued that the operation was equivalent to medical sensationalism, to the detriment of Baby Fae, her family and the baboon. They claimed to be "against the sacrifice of a healthy animal to prolong the life of a sick human being³. Thus, about thirty individuals took turns day and night to brandish placards reading: "research on animals is scientific fraud"; "those scientists who use animals are quacks", and so on. This presence immediately attracted journalists who relayed the cause. For example, a *Time Magazine* journalist wrote that anti-vivisection activists qualified the operation as "ghoulish tinkering" between human and animal life⁴. She emphasized that these activists saw the experiment on Baby Fae as futile, except for the doctors' career advancement, and augured a world where animals would systematically be bred and killed for the needs of organ transplants. In short, from their perspective the attempted xenograft brought sharply into focus the more general question of experiments on animals and the objectification of non-human bodies for scientific and medical research (JASPER & NELKIN, 1992: 122).

Interestingly, these "animal rights" activists did not limit themselves to criticism focused on the animal; they also denounced the treatment inflicted on Baby Fae. In this respect

³ *The Dallas Morning News*, 29 October 1984, "Surgeon defends baboon-heart transplant".

⁴ *Time*, 12 November 1984, "Baby Fae stuns the world".

they also spoke “on behalf of” the humans. For example, M. Gianneli, the representative of the Fund for Animals, raised the following question: “If the team did not even endeavour to explore alternatives to the xenograft, how could the parents have given informed consent?” This echoes the work of historian Susan Lederer (1995) who has shown how, in the first part of the 20th century in the USA, experiments on human beings were initially denounced by activists in anti-vivisection non-profit organizations. The militants believed that experiments on animals could be the first step towards experiments on humans.

This criticism by animal rights activists was relayed by many doctors who felt that xenografts still seemed too uncertain. They argued that the operation could therefore be considered as an experiment on a human being. For example, Doctor Fadali of the University of California claimed that the decision to use an animal organ had been “bravado” and that a human heart “would have given the child a better chance of survival”⁵. Within the medical world criticism stemmed from two distinct groups: those who felt that the parents should have been given the possibility of having a human heart, for feasibility and therefore technical reasons; and those who considered that it was reprehensible to kill an animal when the heart of a deceased human could have been found, and whose argument was therefore of a moral order⁶. In the former case they were defending the human recipient against an experiment; in the latter they were defending the “donor”, unfairly killed since a human donor could have been envisaged – implying a donor whose availability was less problematical.

Leonard Bailey and his team naturally responded to criticism. Bailey said, for example, that he sympathized with the animal rights activists’ cause, but that the difference between humans and other species authorized the objectification of the latter when a human life was at stake. At a press conference he declared: “there is no question in this affair of pointlessly sacrificing animals. We are forced here to make a choice. We can either decide to leave

⁵ *Time*, “Baby Fae stuns the world”.

⁶ *New York Times*, 30 October 1984, “Baby with Baboon Heart Better; Surgeons Defend the Experiment”.

these babies to die, because they are born with half a heart, or we can decide to act and thus to sacrifice forms of life inferior to our species." The American Heart Association relayed this position in the press⁷.

It is noteworthy that the advocates of the operation agreed that the 'sacrifice' – to use the term often employed by the accused themselves – did not necessarily stand to reason. They argued, however, that the innovation could provide a solution to the shortage of organs and make it possible to produce grafts under stricter control, which would eventually be surer than allografts. That is for example what the surgeon Reemstma who had performed xenografts in the sixties argued: "Methods have been developed to limit organ rejects. Most of these tests are feasible only when the donor is an animal, because when the donor is human, time is critical and some invasive procedures cannot be carried out⁸." In other words, because the objectification of animal bodies could be taken further than that of human bodies, xenografts were highly promising. Hence, the supporters of the innovation implicitly asserted a 'naturalism', to use the term proposed by Philippe Descola (2005), that is, a physiological resemblance between the human and the animal that allows for substitution, but a moral difference that legitimizes the availability of animals' bodies for medical activity. It was precisely this separation that was challenged by the animal rights movements. Their question was: How can one recognize this biological similarity between humans and primates, yet treat the latter as mere spare parts?

This controversy was a turning point in the history of transplantation and put a stop to research for ten years. When research was resumed in the 1990s, in both the United States and Europe the animal donor was no longer a primate but a pig, also physiologically similar to humans but whose objectification triggered less protest. In fact, following the Baby Fae controversy, the idea of sacrificing primates for the needs of transplantation was no longer tolerated. This was a radical change in the history

⁷ The San-Diego Union-Tribune, 30 October 1984, "Baby Fae off Critical List; Surgery Draws Criticism".

⁸ *New York Times*, 17 November 1984.

of transplants. Whereas until then it had been total availability that characterized “animal donors” and made them attractive, this new unavailability of animals made the availability of certain humans slightly more legitimate, for instance individuals in a state of “cerebral death” or anencephalic babies in the USA. Yet the fact remains that the availability of these bodies, contrary to appearances and to the prevailing medical discourse, is also still problematical, as we will now see in the second case study.

The two deaths of Christophe

In July 1991, 19-year-old Christophe, the son of Alain and Mireille Tesnière, was killed in a bicycle accident in Dieppe⁹. Christophe was put into intensive care, in a coma. On Monday 5 August, his parents learned that he was “brain dead”, which made him a candidate for organ donation. In France, the Caillavet Act of 1976 authorized the removal of organs “for therapeutic or scientific purposes, from the corpse of a person who, during his or her life, has not made his or her refusal of such a removal known”. This law had been preceded by the Jeanneney Circular in 1968, which had introduced the notion of “brain death” into French law. Humans in an advanced state of coma thus appeared in the 1960s as the best source of grafts, first because they provided living, viable organs, and second because the removal of organs from live subjects was largely perceived – especially in France – as harmful to the donor’s life.

As Christophe had never given his opinion on organ transplantation, in terms of the law he was presumed to be a consenting donor. The doctors nevertheless asked his parents for their opinion and they agreed. A few months later, however,

⁹The analysis drew on a corpus of 59 press articles directly devoted to the Amiens controversy, in *Le Monde*, *Libération*, *Le Figaro*, *La Croix*, *Le Nouvel Observateur*, *Le Quotidien de Paris*, and *Sud Ouest*. The corpus was enriched by documents written by Alain Tesnière from 1993 until now. Together with F. Paterson (Center for Sociology of the Innovation) I interviewed M. and A. Tesnière at their home, in 2009.

Christophe's parents discovered that multiple grafts had been taken from their son's body, whereas they had agreed to only four of them. "Apart from the heart, the liver and the kidneys, they also included the thoracic aorta, with the large upper trunks of the cross, the iliac and right femoral artery, the two internal long saphenous veins and the right femoral vein. We also learned that, after removing the corneas, the eyeballs were placed on the corpse, and that all the incisions were sewn up 'with a metal wire in the thorax'¹⁰." So, the doctors had removed Christophe's eyes, which was prohibited by law because the donor had not stipulated his or her agreement in a will. His parents consequently laid charges against France-Transplant, the organization in charge of transplants in France at the time. The Tesnières denounced the principle of presumed consent, and started to advocate for the switch to a system of explicit consent, in which organs would be removed only from people who had authorized their use after their death. They considered that the Caillavet Act had led to what could effectively be called a nationalization of bodies, and that it allowed for all kinds of abuse. The doctors defended themselves by pointing out the shortage of organs, and thus the existence of receivers in distress, which they claimed legitimized the French legislation. If no refusal had been expressed by the donor, the surgeons could use his or her body and remove the organs that they wanted, thus obtaining a large number of grafts. They nevertheless conceded that the removal of multiple organs could be difficult for the families to accept, and that the families' opinion therefore had to be taken into account more fully. The 1994 bio-ethics laws were based on this approach. They reinforced the importance of the family's opinion and allowed it to refuse an organ removal. Yet they also ratified the Caillavet Act, thus excluding any switch to a system of explicit consent.

But let's go back a little in time. Whereas the debate was veering towards legal issues, in 1992 the Amiens affair also raised questions on the notion of brain death and the resulting experience with organ removal. In the 10 August 1992 issue of the

¹⁰ *Le Monde*, 18 May 1992, Jean-Yves Bau, "La mort violée".

French daily *Libération*, psychologist Marie-Frédérique Bacqué wrote that she saw a reflection of fear in the parents' attitude: "from time immemorial, the dead body has been a ritual object to try to allay the fear that it inspired. Particular value is attributed to the eyes, because they also represent the more or less benevolent 'gaze' of the deceased on those who remain. This explains the complaints of families who have seen the empty eye sockets of their dead relative." Here, indignation is seen as the result of fear: a response to the discomfort, to reassure and to defend a more rational perception of death. Yet the psychologist goes on to make a comment which contradicts an approach centered only on the existence of a "biased" perception. She points out that "to obtain grafts that can effectively fulfill functions, it is necessary to maintain them for as long as possible in a natural environment. Agreement for organ donation therefore implies switching off the equipment that is keeping the brain-dead subject in a state of vegetative survival. Taking part in that decision means contributing to the death sentence¹¹. In this new system, organ removal requires the family's participation in the decision that leads to the person's effective death. The subject from whom the organs are taken is therefore in reality not a body-corpse, even if it is so from a legal point of view, but rather a "living dead", a hybrid being who, although dead, is not yet so. It is this in-between status that makes it so valuable for medicine. The individual whose organs have been removed is both a living human being, which makes the objectification of his or her body problematical but also makes it possible to obtain viable grafts, *and* a dead human, which authorizes the use of his or her organs for the purpose of "giving" them to another human – even though this requires an invasive act leading to final death. Thus, we are far from just fear faced with a human body. The same conclusion was also drawn by some doctors who, during the affair, spoke about their own difficulty as regards organ removal. For instance, Professor Benoit explained that "it's no fun removing [body parts]. One has to be devoted because the patients arrive in a state of

¹¹ *Libération*, 10 August 1992, "Travail de deuil, transfert d'organes".

brain death. But with all the respiratory equipment, they have the complexion of a living person. After the removal that's no longer the case [...]. The idea that we, surgeons, can be insensitive to a body is pure fantasy¹²". A different albeit minority point of view is thus expressed: the surgeon is a man like any other, troubled by the activity of removing a part of an individual who is both dead and alive. Note however that this type of statement is devoid of criticism of the actual concept of brain death: if we look at Professor Benoit's discourse, we see that beyond appearances there is indeed a dead individual. This seemingly obvious fact was what Alain Tesnière undertook to challenge, based on various studies from the scientific and medical world.

In 1996 the Tesnières' case was dismissed – but the controversy was by no means over. Even though the media's interest in the issue declined, Christophe's parents continued to denounce the problems posed by organ removal. His father began to investigate transplantation and subsequently published many articles in the press and sometimes in more academic journals. In this case a tragedy was the motivation for a full-blown research activity, in which Alain Tesnière's status shifted from "lay victim" to "expert victim"¹³. In 1993 he published a book in which he set out his point of view on transplantation. He put the issue of uncertainty at the heart of his argument, emphasizing the fact that the notion of brain death "is highly complex and unacceptably fuzzy". In France, for example, the law required a flat electroencephalogram of a duration deemed to be sufficiently long, but the interval was not specified¹⁴. Alain Tesnière furthermore pointed out that to obtain healthy organs, speed was essential. Yet for the donor's family this rush was disturbing: were the doctors not tempted to

¹² *Le Figaro*, 24 January 1994, "Réorganiser la transplantation d'organes".

¹³ Alain Tesnière is currently doing a PhD in philosophy, which he expects to complete in 2011. His thesis is on organ transplantation in France.

¹⁴ Note that the purpose of the Decree of 2 December 1996 was to narrow down the criteria for diagnosing brain death in France. Brain death now demands the presence of paraclinical signs showing "the irreversible nature of encephalic activity": "two EEGs which are nil and a-reactive, performed within a minimum interval of four hours."

act too quickly? These uncertainties prompted Christophe's father to raise the following questions: "What is the status of these living corpses? Are they still people? [...] At what time did Christophe die? Was it on the Monday morning after the electroencephalograms? Was it on the Monday at 4 p.m. as the doctor decided officially by signing the death certificate? Was it after the removal of multiple organs, when the machines were turned off?" (TESNIÈRE, 1993: 43).

Alain Tesnière also studied the debates on "brain death" that arose within the medical community, thus revealing another dimension of the controversy. He referred to scientific articles that highlighted the difficulty posed by the diagnosis of encephalic death.

These debates were actually situated on several levels. The first concerned the number of parts of the brain that had to be concerned to affirm that a coma was irreversible. In Britain the brain stem was enough, whereas for the French and most Europeans the entire brain, the cortex and neo-cortex, had to be dead. The second level concerned the techniques used to diagnose the post-coma stage. Many critics denounced the lack of reliability of the measurement techniques prescribed by the law. The methods available to test the existence of encephalic destruction could be fallible and certain pathological states, such as intoxications or child pathologies, could lead to errors in the diagnosis of brain death (BERNART, 1992). Finally, the third level implied a more fundamental challenging of the concept. Representatives of the medical community claimed that some patients in a state of brain death retained certain functions (e.g. homeostasis or the capacity for gestation) which did not allow for a distinction to be made with people in a chronic vegetative state (SHEWMON, 2009). This claim was disturbing in so far as it meant that the removal of organs sometimes took place on dead people whose state did not actually make it possible to differentiate them from individuals who were unquestionably alive.

Today Mireille and Alain Tesnière are still struggling for the abrogation of the Caillavet Act and for the reality of organ donation to be made known to the public. They maintain that there is a category of human beings today who are both dead and alive, and are no longer considered as people in so far as brain death allows

for the availability of their bodies – an availability whose corollary is invasive acts resulting in actual death. To all their questions on the definition of death and on the violence of organ removal, the advocates of transplantation repeatedly emphasize the shortage of organs, like a leitmotiv: organ removal is a “lesser evil” because it saves other human lives. Members of sanitary agencies and the doctors at the head of organ transplant and removal teams usually treat the families’ doubts as to the donor’s brain death as the result of misperceptions or fears that need to be eradicated. From their point of view, this requires nothing short of educating an ignorant or impressionable ‘public’. Yet, as Christophe’s parents emphasize, within the medical world itself there is controversy over the notion of brain death.

To conclude, I would like to revert to a simple question: what are the conditions under which transplantation can take place? To perform a transplant, there has to be an available donor who is compatible with the receiver’s body. The problem is that these two conditions are often mutually exclusive. From the point of view of compatibility, the ideal situation would be to remove organs from a person who is alive, as a corpse does not provide viable organs. But humans are not available *a priori*. Brain death was therefore invented, making it possible to authorize organ removal from humans who were simultaneously dead and alive. The twofold problem of availability and compatibility was thus solved. For the families of these hybrids, the removal of organs can however prove to be intolerable. This fuzzy status is perceived as a construction that denies these individuals’ membership of an existing category: that of a person unavailable for objectification. The conclusion of this article is therefore consistent with Margaret Lock’s argument that the status of hybridity underlies the most compelling questions and fears regarding organ transplantation. I furthermore show that the study of controversy enables us to go beyond this mere statement and to understand how the advocates of transplantation in the broad sense of the term seek to avoid these inevitable questions. They dismiss the families’ criticism as emotional or irrational by activating the distinction between experts and laypersons, arguing that while the former have the knowledge and objectivity to understand brain death, the latter,

inclined to be governed by fear and erroneous representations, can be mistaken. Science studies have for a long time shown the importance of this expert/lay distinction if we are to understand the emergence and success of scientific and technical innovations (CALLON, LASCOUMES & BARTHE, 2001). But in view of the growth of controversy over the concept of brain death, within the scientific community itself, how long can this avoidance be sustained?

From the point of view of the availability of donors' bodies, animals have been seen as the ideal donors since the appearance of the concept of transplantation. Compatibility has however been the stumbling block, for animal grafts are immediately rejected by human bodies. To solve this technical problem, researchers set their sights on primates as they are physiologically and genetically very similar to humans. Thus, it is the near-humanity of primates from a biological point of view that makes them good donors. A 'naturalism' is asserted: physiological resemblance is associated with moral dissimilarity that makes killing and objectifying primates possible. During the Baby Fae affair this naturalism was called into question: the kinship between humans and simians was affirmed, from a biological *and* moral point of view. This quasi humanity challenged the possibility of killing for organ removal. It could be said that the donor primate switched from the status of animal-human to that of human: a person to whom respect is due. Once again, it was the Chimera, the animal-human, that ruffled the boundaries of humanity and triggered criticism aimed at purifying, at imposing a pre-existing category, albeit in a surprising way, since non-humans were to be included in the category of people.

A surprising scale of beings emerges: certain animals, considered as "quasi people" are unavailable, whereas certain humans are perceived as organ reservoirs and therefore as available, because their brain seems to be irremediably damaged. At the same time, the Tesnière affair shows that this availability of humans is also intolerable for some, especially since it is based on a debatable concept, "brain death". In short, the 'disruption' of the boundaries of humanity as a result of biomedical innovations has already taken place. It is a shift that, as I have endeavoured to show here, has led to a process of reassertion of pre-existing categories.

References

- BERNART, James L. (1992) "How much of the brain must die in brain death?", *Journal of Clinical Ethics* 3 (1) 21-26.
- BROWN, Nik (1999) "Xenotransplantation: normalizing disgust", *Science as Culture*, 8 (3) 327-355.
- CALLON, Michel and LATOUR, Bruno (1991) *La science telle qu'elle se fait. Anthologie de la sociologie des sciences de langue anglaise*. Paris: La Découverte.
- CALLON, Michel, LASCOUTES, Pierre & BARTHE, Yannick (2009) *Acting in an Uncertain World. An Essay on Technical Democracy*. Cambridge: The MIT Press.
- DESCOLA, Philippe (2005) *Par-delà nature et culture*. Paris: Gallimard.
- FELLOUS, Martine (2004) "La xénogreffe: enjeux et questions", In Patrick PHARO (ed) *L'Homme et le Vivant. Sciences de l'homme et sciences de la vie*. Paris: PUF.
- FOX, Renée C. and SWAZEY, Judith P. (2002) *The Courage to Fail: A Social View of Organ Transplants and Dialysis*. New Brunswick: Transaction Publishers.
- GODBOUT, Jacques T. (2009) "Le don d'organes: une ressource rare?", *Revue du Mauss permanente* (on line: <http://www.journaldumauss.net/spip.php?article455>).
- JASPER, James M. and NELKIN, Dorothy (1992) *The Animal Rights Crusade: The Growth of a Moral Protest*. New York: Free Press.
- KIRKSEY, Eben S. and HELMREICH Stefan (2010) "The Emergence of Multispecies Ethnography", *Cultural Anthropology* 25 (4) 545-576.
- KOHN, Eduardo (2007) "How Dogs Dream: Amazonian Natures and the Politics of Transspecies Engagement", *American ethnologist* 34 (1) 3-24.
- LEDERER, Susan E. (1995) *Subjected to Science: Human Experimentation in America before the Second World War*. Baltimore-London: Johns Hopkins University Press.
- LEDERER, Susan E. (2008) *Flesh and Blood: Organ Transplantation and Blood Transfusion in Twentieth-century America*. Oxford: Oxford University Press.

- LÉVI-STRAUSS, Claude (1983) *Le regard éloigné*. Paris: Plon.
- LOCK, Margaret (2002) *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.
- MALINOWSKI, Bronislaw (1968) *Une théorie scientifique de la culture*. Paris: Seuil.
- PAPAGAROUFALI, Eleni (1996) "Xenotransplantation and transgenesis. Im-moral stories about human-animal relations in the West", In DESCOLA, Philippe and PALSSON, Gils (eds) *Nature and Society. Anthropological Perspectives*. New York: Routledge.
- SCHLICH, Thomas (1997) *Die Erfindung der Organtransplantation: Erfolg und Scheitern des chirurgischen Organersatzes, 1880er-1930er Jahre*. Frankfurt/M.-New York: Campus.
- SHARP, Lesley A. (2006) "Babe and Baboons. Jesica Santillan and Experimental Pediatric Transplant Research in America", In WAILOO, Keith, LIVINGSTON, Julie and GUARNACCIA, Peter (eds.) *A Death Retold: Jesica Santillan, the Bungled Transplant, and Paradoxes of Medical Citizenship*. Chapel Hill. The University of North Carolina Press.
- SHARP, Lesley A. (2006) *Strange Harvest. Organ Transplants, Denatured Bodies, and the Transformed Self*. Berkeley: University of California Press.
- SHEWMON, Alan (2009) "Brain death: Can it be resuscitated?", *The Hastings Center Report*, 39 (2) 18-24.
- TESNIÈRE, Alain (1993) *Les yeux de Christophe. L'affaire d'Amiens*. Paris: Editions du Rocher.
- WAISSMAN, Renée (2001) *Le don d'organes*. Paris: PUF.

FROM THE EXPERIMENTAL BODY
TO THE EXPERIMENTAL PATIENT.
MEDICAL EXPERIMENTATION IN NEUROSCIENCE

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Biomedicine is not simply an intensification of the links between fundamental and clinical research¹, which can be observed in the incorporation into medical practice of tools and methods from the laboratory. This “scientific” medicine is characterised by a major reconfiguration of clinical and therapeutic practices, alongside the emergence of new entities and new actors. Thus biomedicine appears not solely as changes or adaptations in pre-existing medical practices, but as a process of (re)creation of new practices that are articulated in socio-technical collectives associating medical entities, structures, technologies or humans, in which the disciplinary boundaries are shifting (CAMBROSIO, KEATING, SCHLICH, *et alii*, 2006; CLARKE, SHIM, MAMO *et alii*, 2003; KEATING and CAMBROSIO, 2003; LOCK and GORDON, 1988; LOCK, YOUNG and CAMBROSIO, 2000; RABÉHARISOA and BOURRET, 2009).

This article sets out to explore this dimension of contemporary medicine, focusing on the forms of medical practice that arise from the application of therapeutic biotechnologies. The purpose is to describe how the use of a neurosurgical technology, Deep Brain Stimulation (DBS), for the treatment of neurological and psychiatric disorders creates new configurations of collective practice, by (re)aligning the objectives and practices of a variety of actors, and by developing new entities over the course of its experimental development. To do so, I follow these entities and

¹ And between laboratories and industry (GAUDILLIÈRE and LÖWY, 1998).

actors in different spaces and times (in the consultation room or the operating room, in a staff meeting or a psychiatric ward, through the clinicians discourse or the patient's care) in order to describe the plurality and coexistence of their combinations and reconfigurations around the uses of DBS.

DBS was invented in 1986 by a French neurosurgeon, Professor Bénébid, and was originally used for treatment of Parkinson's disease (PD) and essential tremor (BENABID, POLLAK, LOUVEAU *et alii*, 1987). Two small electrodes linked to a pacemaker placed in the chest are surgically implanted in deep brain structures to modulate their activity by continual high-frequency stimulation. DBS is reversible and adaptable; the neurologist can adapt the stimulation parameters using an external 'programmable device' to obtain the best clinical improvement. It is, however, a symptom-targeting treatment: it improves the clinical state of the patient but does not cure him/her.

Today, this technology occupies a position of major importance in neuroscience, for both research on and treatment of various neurological disorders (PD, epilepsy, dystonia, essential tremor, chronic pain) and psychiatric or neuropsychiatric disorders (depression, obsessive compulsive disorder, Tourette's syndrome).² It is currently one of the most efficient treatments for PD. Over the last ten years, the number of publications on these applications has grown exponentially. However, this technology remains partially experimental. Its mechanisms of action are uncertain and debated (KRINGELBACH, JENKINSON, OWEN, *et alii*, 2007). Moreover, certain complications and behavioral or cognitive adverse events can occur, sometimes with dramatic consequences (see BURKHARD, VINGERHOETS, BERNEY *et alii*, 2004).

² The *Food and Drug Administration* approved DBS as a treatment for essential tremor and PD in 1997 and 2002, and dystonia in 2003. FDA also approved "humanitarian device exemption" for DBS for severe obsessive compulsive disorder in 2009. In France, a national decree authorized the reimbursement of DBS procedure for PD by the French national health insurance in 2005.

On the history of DBS and its applications, see: DANISH and BALTUCH, 2007; PERLMUTTER and MINK, 2006; SCHWALB and HAMANI, 2008; TALAN, 2009.

This paper describes how the introduction and application of this experimental therapeutic technology to neurological and psychiatric disorders (PD, Tourette's syndrome and obsessive compulsive disorder) in a French hospital ward opened up a specific neuropsychiatric field of practice. It will also show how this field is divided into two different configurations of practices: the first one is a neuropsychiatric collective of practice in which DBS and an 'experimental body' allow clinicians and researchers, psychiatrists and neurologists, to cooperate and share similar objectives; in the second configuration, while clinicians are organizing the patient's care, two new forms of collective practice are emerging (the "psychotherapeutic" care and the "psychopedagogical" care) which are redistributing the clinical skills. How do these two configurations, linked by the same technology and coordinated around the patient, coexist at one and the same time? How do they reconcile different actors and entities with their distinctive skills and ontological qualities? Who are the actors involved in this practice? What kind of biomedical entities are mobilised? How does DBS contribute to articulating them? And finally, what are the specificities of this collective medical practice?

To explore these questions, I followed the team at the *Clinical Research Center* (CRC) of a French hospital for four years (September 2004 to December 2008). This CRC is a neuroscience center that brings together researchers and clinicians devoted to therapeutic experimentation and more specifically to the application of DBS for the treatment of neurological and psychiatric disorders. The ethnographic research was articulated around the development of a clinical trial for the application of DBS to patients suffering from obsessive compulsive disorder (OCD)³ who are resistant to

³ In the American Psychiatric Association's classification of mental disorders (DSM) (2000), OCD is defined by obsessions (intrusive and anxiety-producing thoughts, such as preoccupations with sexual impulses or fear of contamination), and compulsions (repetitive ritualized behavior, such as repetitive hand washing or hoarding). The patient has to execute these compulsions to reduce the anxiety induced by the obsessions. The current treatment is serotonin reuptake inhibitors combined with cognitive behavioral therapy. With these treatments, however, 25 to 40% of patients have persistent symptoms.

all conventional treatments (MOUTAUD, 2008, 2011).⁴ In addition, as the CRC has been implanting PD patients since its creation in 1996, and Tourette patients since 2001, it was possible to study the delivery of care in the framework of this procedure more generally (selection of the patients, surgery, consultations, team meetings, etc.). I additionally carried out more than 50 semi-structured interviews with the entire CRC staff (neurosurgeons, neurologists, psychiatrists, psychologists, neuropsychologists, neuroanatomists, nurses, and laboratory technicians) and implanted patients.

The specificity of CRCs in French hospitals is that they are sites open to clinicians and researchers where they can collaborate on research and clinical trials (MOUTAUD, 2010). They are hospital wards at the interface between medical research and clinical practice, experimentation and therapy. What makes a CRC indispensable in this perspective (LATOUR, 1992) is that it is a “trading zone” (GALISON, 1997)⁵: a neutral and intermediate place, a crossing point where individuals from various scientific cultures or communities of practice can collaborate and coordinate their activities, create hybrid languages and activities between the lab bench and the bedside (LÖWY, 1997). CRCs provide their equipment, administrative organization, nurses and laboratory technicians for this purpose, and guarantee the specific conditions of medical research and its procedures (such as ethical rules and guidelines).

First, let us see how the CRC found in DBS a tool for combining the various interests of clinicians and researchers, psychiatrists and neurologists. I will then consider the transformations imposed by this technology in the care of the patient.

⁴ Seventeen patients have been implanted in France (MALLET, POLOSAN, JAAFARI *et alii*, 2008).

⁵ See also LÖWY, 1992.

*DBS and the creation of a neuropsychiatric field of practice**FROM ONE CASE TO THE NEXT:**THE EMPIRICAL DEVELOPMENT OF DBS AT THE CRC*

During the first years of DBS use for the treatment of PD, neurologists reported adverse emotional and behavioral events in patients under stimulation. These effects were clinically similar to psychopathology (such as hypomania, depression, hypersexuality, apathy, pathological gambling) (see APPLEBY, DUGGAN, REGENBERG *et alii*, 2007). They were triggered in surgical or post-surgical conditions (and for the most part were reproducible), and disappeared when the stimulation was turned off or when the parameters were modified.

For example, in 1998 at the CRC, a female PD patient experienced transient acute depression when stimulation was delivered. The effect was visually spectacular with a major “on/off effect”⁶: in a few seconds the patient started to cry, expressing despair and begging to die. When the stimulation was turned off, she recovered her normal state (BEJJANI, DAMIER, ARNULF *et alii*, 1999). A neurologist in the CRC team explained to me: “This experiment marked a turning point: from then on we could act on mental states and emotions, not just on motor function.” This famous experimental case opened up new lines research and clinical prospects.

Following this, in 1999, the CRC team decided to implant a patient suffering from Tourette’s syndrome (TS). This rare syndrome is historically shared between neurology and psychiatry (KUSHNER, 1999). It is a variable association of motor and phonic tics with behavioral disorders (such as OCD, depression, hyperactivity or self-harm behaviors). As it involves both neurological and psychiatric symptoms it is “a specimen at the crossroads of neurology and psychiatry”, as remarked by the same neurologist. For the team, it provided a theoretical model for an extension of

⁶ A “major on/off effect” means that there is a major and rapid (visually) clinical effect on the patient when the stimulation is alternatively turned on and turned off.

DBS applications to mental disorders, also leading to cooperation between neurology and psychiatry. The neurologist explained: "Taking a TS appeared to be the best way to experimentally modulate emotions." The first patient was a severe case (motor tics since the age of 7 with impulsivity, self-injury, borderline disorder and depression). She was implanted in 2001 and the effects were very promising.⁷ The neurologist noted: "She was a difficult patient but she enabled us to experiment and be innovative".

In 2002, two PD patients implanted at the CRC reported that their comorbid OCD symptoms had also surprisingly disappeared under stimulation (MALLET, MESNAGE, HOUETO *et alii*, 2002). With these two new empirical and unexpected cases, DBS demonstrated its ability to improve behavioral and mental disorders. It then became possible to open up a new field of practice in France, extending the use of DBS to purely psychiatric disorders such as OCD. These successive experimental cases and the subtle moves they involved from motor functions to emotions, from neurology to psychiatry, provided for the CRC a foundation on which to develop research on DBS effects in OCD, and were used as scientific and ethical arguments to support it.⁸

THE EMERGENCE OF AN "EXPERIMENTAL BODY"

In the course of its experimental use at the CRC, DBS and these empirical cases have fundamentally altered not only the relationships between neurology and psychiatry but also between clinicians and researchers. They became linked by shared objectives in experimental research and patient care. The psychiatrist interviewed at the CRC remarked:

I have always reasoned from a neuroscientific point of view. I have always studied the brain and its mechanisms. But it was not fully satisfactory. DBS and the Parkinson cases provided me with practical examples to study.

⁷ 60 months after surgery, DBS induced an 82% decrease in tic severity and a dramatic reduction in self-harm behaviors, impulsiveness, anxiety and depression (HOUETO, KARACHI, MALLET *et alii*, 2005).

⁸ As well as animal models (see GRABLI, MCCAIRN, HIRSCH *et alii*, 2004).

DBS offers the opportunity to explore the links between mental states and emotions and brain functioning. Neurologists and psychiatrists can explore these links clinically and also functionally *via* direct local action on the brain. DBS, in an empirical manner, has challenged the naturalization of mental processes and opened up a common neuropsychiatric field of action. Within this field, no clinical phenomenon is simply “neurological” and nor is it simply “psychiatric”: they all need the association of the skills of these both fields to be clinically and experimentally investigated.

Further to this, DBS also brought together the interests of researchers and clinicians. As for the transient depression case we described above, DBS enables neuroscientists to create experimental clinical models of syndromes and reproduce them in patients. Indeed, DBS allows the modulation of the activity of targeted brain structures, and to experimentally produce clinical outcomes in terms of symptoms. Clinicians can then correlate these results with the functional sites stimulated. DBS is therefore becoming a powerful tool for experimentally exploring the human brain functions *in vivo*. Various lines of research in brain imaging, neuropsychology or neurophysiology can be developed in this empirical setting. For example, at the CRC, two PD patients who experienced transient hypomanic states when they were stimulated gave their consent to have this clinical state reproduced for one day.⁹ During this time, the CRC team performed several clinical evaluations (motor, cognitive, and behavioral evaluations) and a functional neuro-imaging examination in order to explore the brain mechanisms that underlie this behavioral disorder (MALLET, SCHÜPBACH, N'DIAYE *et alii*, 2007).

Thus, in conditions such as these, the patient becomes an “experimental body”: an entity that can be used to investigate normal or abnormal body functioning (LÖWY, 2000). This experimental condition begins during the surgical procedure and the implantation of electrodes, for example when clinicians and

⁹ In the DSM (AMERICAN PSYCHIATRIC ASSOCIATION, 2000) a hypomanic episode is a mood disorder characterized by “persistently elevated, expansive or irritable mood”. Symptoms such as psychomotor agitation, distractibility, logorrhoea, impulsivity or aggressiveness can be observed.

neurophysiologists explore and record physiological brain activity while the patient is subjected to motor or cognitive tasks.¹⁰ But this condition is not limited in time and continues as long as the patient is implanted and stimulated because throughout this entire time, adverse effects might appear (even if fewer will appear following the stabilization of the stimulation parameters after few months).¹¹ These experimental models translate neurologists' and psychiatrists', clinicians' and researchers' research questions into clinical facts or therapeutic aims and enable them to cooperate: thus, each side effect (whether psychic, cognitive or vegetative) and each clinical improvement can potentially initiate new applications or new pathophysiological hypotheses.¹² In this perspective, DBS can be included in the history of the electrical exploration of human brain functions in neurosurgical practice (see the introduction by the author in MALLET, BUOT, MOUTAUD *et alii*, 2008: 27-29; and BRAZIER, 1988; FINGER, 1994; WALKER, 1957, for a historical perspective).

¹⁰ The surgical implantation of the electrodes is performed under local or reversible anesthesia.

¹¹ Patients could be aware of this experimental condition. This is how a patient who experienced a hypomanic state described what she felt to the neurologist in consultation: "I'm excited... Why do I act like this...? I've never been like this in my whole life. I'm tired of being like this. Something has changed inside me, but what is it?" And this is how an OCD patient implanted who also experienced a hypomanic state explained to me what happened: "I don't know if the stimulation was too strong but I felt something because I couldn't stop talking, I was restless and I couldn't eat and couldn't sleep. Then I was hospitalized in emergency in the psychiatric hospital Y. I was so overexcited that they thought I was crazy. I was turning around the bed and they locked me in an isolation room. This is when I realized that I had mood fluctuations: sometimes I felt good and then I started going crazy. Sometimes I felt very down, and I thought they locked me up for an experimental purpose. I started going mad."

¹² For example, see these different cases concerning memory (HAMANI, McANDREWS, COHN *et alii*, 2008), minimally conscious state (SCHIFF, GIACINO, KALMAR *et alii*, 2007), addiction (WITJAS, BAUNEZ, HENRY *et alii*, 2005), or obesity (PISAPIA, HALPERN, WILLIAMS *et alii*, 2010).

NEUROSCIENCE IN ACTION

It appears that the success of this technology, apart from its therapeutic efficiency, is that it shares many lines of interest with research and clinical practice in the neuroscientific field. The focus chosen in this chapter in the history of this development is the empirical elaboration of a socio-technical system at the CRC: this elaboration has opened up an empirical field of neuropsychiatric practice partially articulated around the ‘experimental body’; a ‘collective of practice’, which could be defined as a “bioclinical collective” (RABÉHARISOA and BOURRET, 2009), composed of clinicians and researchers who have gathered around its development and a federative research strategy.¹³ Thus DBS can be taken as an example of what could be called “neuroscience in action” in clinical and therapeutic practice. Neuroscience explores normal and pathological brain anatomy and function with two interrelated objectives: first, to identify and understand the neural bases of cognitive functions, thought and behaviors; secondly, to discover the causes of neurological and psychiatric diseases and find treatments for them (EHRENBERG, 2011). This neuroscientific program draws substance from the development of DBS. Furthermore, while the collaboration – or even the merging – of neurology and psychiatry has been claimed or wished for since the 1990s by neuroscientists in a large number of articles and letters in scientific journals, it is DBS – as a promising therapeutic technology – that is generating a therapeutic alliance in the care of the patient.¹⁴ This technology is confirming the shift from theory and research on brain activity to the development of efficient effective treatments for mental and neurological disorders. The “great divide” between neurology and psychiatry – between brain

¹³ A bioclinical collective “brings together researchers and clinicians from different disciplines and specialties, and strongly interconnect the clinic and the research” (RABÉHARISOA and BOURRET, 2009: 693).

¹⁴ See these few references among a hundred: BAKER, KALE and MENKEN, 2002; DAROFF, 1990; KANDEL and SQUIRE, 2000; MARTIN, 2002; PIES, 2005; PRICE, ADAMS and COYLE, 2000; YUDOFKY and HALES, 2002.

diseases and mind disorders – will be filled in, and the electrodes will bring them together through the brain.

From an 'experimental body' to an 'experimental patient'

A second configuration of practice begins at the CRC when the patient is chronically stimulated. As the patient, an 'experimental body', becomes an 'experimental patient', a new style of practice with new objectives appears. This second configuration is a part of the same socio-technical system and shares the same actors or entities, but with new identities and a redistribution of knowledge and skills. We will see how this configuration is subdivided into two sets of practices with similar objectives, but objectives that give different values to this collective organization of care.

PSYCHOTHERAPEUTIC FOLLOW-UP CARE

After the research procedure, when they were under regular stimulation, OCD and TS patients encountered difficulties in social adaptation. They reported that their symptoms had practically disappeared but that they were returning to a daily life that had been devastated by the disease. Before surgery they could no longer work and the disease was interfering with their personal relationships. During our interviews, they described these everyday problems – in relationships, in their families, at work – as part of their disease, which was no longer just symptoms and a disorder (whether mental or biological) but also had consequences on life that become a constituent part of the disorder. In a rather confused manner, these problems were seen as much as the consequence as the source of an abstract state of "ill-being". In the discourse of all the patients there was the idea that getting back to "normal" had to include recovering a balance in their daily lives.

To address this partially expected situation (patients included in this research trials had had severe symptoms for

several years, they were resistant to all conventional treatments and were de-socialized), the CRC offers multidisciplinary care articulated around psychiatric follow-up care. DBS has proved to be effective for alleviating the symptoms, but the CRC team objective is now to take the patient to as high a level of social adaptation as possible.¹⁵ On one hand the neurologist is in charge of the optimization of the stimulation, and on the other hand the psychiatrist provides “psychotherapeutic” follow-up care (the terms used by CRC: WELTER, MALLET, HOUETO *et alii*, 2008: 954). This procedure aims, once the symptoms have been reduced under the effect of DBS, to support and accompany the patient in his or her social reintegration and adjustment process. For the medical team, it adds up to listening, supporting and counseling, associated with psychopharmacological prescription if required. As I indeed observed, during a consultation the psychiatrist could for example decide when a stimulated OCD patient should try to get a job; help him to deal with his alcohol abuse; or decide to admit him to a psychiatric unit. This set of “psychotherapeutic” practices – made possible by the effects of DBS on symptoms – give prominence to clinical skills, with a clear distinction between neurological and psychiatric clinical intervention, delimited in space, time and their objectives. In addition, DBS offers a new dynamic to this form of care, which previously appeared ineffective on such severe cases. As in the descriptions by Ehrenberg (2009) of psychopharmacology and shock treatments during the 1960s in France, these treatments have given a new dynamic to psychotherapeutic interventions among patients freed from their symptoms. DBS, like psychopharmacology, has provided new access to another dimension of disease and to the patient. It makes the patient “more amenable to psychotherapy” (*ibid.*: 88). The CRC team is thus able to focus on the other facet of disease: social adaptation.

¹⁵ OCD or TS patients’ social adaptation problems (or “functioning”, the notion used for mental disorders in the DSM and psychiatric practice: AMERICAN PSYCHIATRIC ASSOCIATION, 2000) are one of the major ethical and humanist arguments used by researchers to legitimate DBS experimentation in such cases.

PSYCHOPEDAGOGICAL FOLLOW-UP CARE

The situation found among OCD and TS patients may seem close to the situation of some PD patients implanted at the CRC. As I described elsewhere (MOUTAUD, 2008, 2011; see also GISQUET, 2008), in the early 2000s, the neuroscientific team was surprised to observe that some PD patients once stimulated were “not happy” (a neurologist), whereas they showed a great improvement in their motor symptoms and the clinicians and researchers were very satisfied with the conclusive DBS results. For the motor symptoms, the technique had proved to be very effective (see KRACK, BATIR, VAN BLERCOM *et alii*, 2003). The literature has also reported considerable improvement for patients in their quality of life (DIAMOND and JANKOVIC, 2005). However, in some PD patients, their experience of this improvement and of the advantages of stimulation does not match the results, and their behavior is sometimes unsettling for the CRC team, as indicated in the title of one of its articles: “Neurosurgery in Parkinson’s disease: the doctor is happy, the patient less so?” (AGID, SCHÜPBACH, GARGIULO *et alii*, 2006). These patients were not satisfied or did not experienced any social readjustment: some of them gave up their work even though they had fought to preserve it during their worst motor states; others complained that the stimulation did not work, or that they did not feel the benefit of it. Sometimes it was the family who complained that they did not recognize the patient or could not cope with his new way of life. In some cases, the conflict led to a divorce, or the patient came to hope for a return to the former condition and life. But in fact, none of them wished to stop the stimulation.

The CRC team asserts that such problems are not the result of adverse effects of DBS: the PD patients do not have behavioral or cognitive disorders that might explain their problems. The dimensions involved here are not pathological, but what the team identifies as issues of social adjustment. Although their motor disability is attenuated, the patients are not “socially adjusted”, as a neurologist explained, and have “trouble fitting into their family and professional environment”.

The CRC has categorized all these cases and the problems observed in them as pertaining to the field of “psychopedagogy”: thus DBS is seen as causing a rupture in the patient’s life, for which he or she (and/or his or her close relations) is not always prepared, and this is then expressed psychologically by dysfunctions in his/her social relations or by discontent. It is because DBS improves the patient’s symptomatic state radically and suddenly, that the patient is having trouble. For the CRC, these patients have “a distressed mind in a repaired body” (SCHÜPBACH, GARGIULO, WELTER *et alii*, 2006). They are therefore not able “to make the proper adjustment” (a psychologist): they can have problems with their partners, have lost the meaning of their lives because they are no longer focused on fighting the disease, the disability, and the specific stigmatization of the symptoms they previously experienced.

The most important aspect in this CRC team explanatory model is the categorization of the problems that it implies. If these problems are not caused by DBS and its effects on the brain’s functioning, this means they are either psychological, or adaptive and pedagogical. This initiates a new form of care. The team’s solution is here to support, accompany, and explain. It provides multidisciplinary “psychopedagogical” care (as the CRC named it) which involves all the clinicians, intended to optimize the effectiveness of the treatment by engaging in a process of follow-up and support, including information on the effects, limits, and potentialities of DBS (see Moutaud, 2011).

The “psychopedagogical” field thus cuts across forms of intervention that are completely distinct from neuroscience and from brain causality, and have no disciplinary specificity: it entails opening up a field of action and care focused on prevention and long-term psycho-social rehabilitation. These problems appear as multi-dimensional, with several different overlapping causes or reasons – biological, psychological, and sociological – none of them exclusive of the others, hence the team’s difficulty in defining them, whether in terms of their origin, the category of patient, or the diversity of events that they cover. As in OCD and TS, DBS and its effects on cerebral functioning are not, in cases such as these, sufficient to improve patient condition because symptom

alleviation does not necessarily imply an improvement in social adaptation.¹⁶ Certain psychological or social processes seem to question the device. The patient should therefore be integrated into a multidisciplinary perspective in which the care objectives shift to a non-delineated field. This collective “psychopedagogical” care program needs to define the profiles of these unexpected unstable entities and to stabilize them.

However, some of these PD patients have reversed this model of explanation. For them, DBS is the cause of their problems and/or the solution to them. These patients, as I observed during consultations, ask to be stimulated according to their subjective experience so as to solve problems that they see as having appeared following the effects of the technique. These are patients who will ask for the parameters, which they believe to be not properly set, to be adjusted, for stimulation to be increased, or who think that it has stopped. There are also spouses who want the neurologist to change the stimulation settings (or to stop it) in order to modify the behavior of the stimulated patient, or wanting the patient to return to what “he was before” (SCHÜPBACH, GARGIULO, WELTER *et alii*, 2006: 1812). In such cases, DBS seems to generate a new category of patients at the CRC to whom the team now needs to attend. The ‘experimental body’ that emerged in the first configuration thus becomes an ‘experimental patient’: individuals involved in clinical care but who upset the care program (in this case the “psychopedagogical” care configuration) and force – in this unstable situation – the clinicians to readjust to this new condition

TESTING THE NEUROSCIENTIFIC PROJECT

Unlike “psychotherapeutic” care for OCD and TS patients, the “psychopedagogical” approach does not give prominence to the clinical skills and status of the actors and entities involved. The uncertainty of the situation blurs clinical characteristics. Indeed, if the neuropsychiatric field of the first configuration described is based on a cross-sectional and non-determined multidisciplinary

¹⁶ On this question, see for example: LLOYD and MOREAU, in press.

organization which makes it possible to question unexpected events and entities, the “psychotherapeutic” field is a ‘collective of practice’ which has to deal with the uncertainty produced by deficient explanations and undetermined and non-stabilized entities (RABÉHARISOA, 2006; RABÉHARISOA and BOURRET, 2009). While the neuropsychiatric program is creating a new way of producing knowledge and therapeutics, “psychotherapeutic” care configuration is recycling preexisting clinical traditions to optimize the effect of DBS; and finally “psychopedagogical” care is based on the very uncertainty of the ‘experimental patient’s’ clinical situation, and it is trying to stabilize and to contain blurred objects and entities. This last configuration has to deal not only with social adaptation problems but also to prove the strength of the “psychopedagogical” explanatory model. It is shaking the foundations of CRC first configuration of practice and its scientific and therapeutic objectives. In the “psychopedagogical” care configuration, DBS application becomes a test for the neuroscientific program.

Conclusion

When they are included in the DBS socio-technical system, actors and entities are spread across two distinct configurations of practice in which they coexist in different forms and identities, and with different skills or clinical specificities. Upstream of the therapeutic use of DBS we found the patient’s ‘experimental body’ and a neuropsychiatric disorder located in the brain. Neurology and psychiatry shared the same language and explanatory models. But in a second configuration, when the stimulation is turned on, the patient needs a global care configuration in which the main goal is his/her social adaptation. The disorder becomes a part of life and the patient – in his/her labile condition – can try to appropriate the therapeutic technology (MOUTAUD, 2008, 2011). Neurologists and psychiatrists have to redefine their roles and skills. On the other hand, the uncertainty of the ‘experimental patient’s’ condition could reinforce the links between clinicians and researchers while the CRC team continued to explore more

neuroscientific explanations for ill-being and social maladjustment. These two configurations are not mutually exclusive and can coexist. They are both made up of research and clinical practice, neurology and psychiatry; they cannot be differentiated by these oppositions (and they can emerge at any time in any spaces, even outside of laboratory conditions or the “biomedical platforms”: KEATING and CAMBROSIO, 2003). They are differentiated within the dimension of the disease and the patient’s state, which polarise the socio-technical system and define the roles.

The ‘experimental body’ and the ‘experimental patient’ are the same biomedical entity in two separate collective of practice. However, the ‘experimental patient’ is not only the reaction of the ‘experimental body’ when he is incorporated in the patient’s care program – as the “psychopedagogical” model would explain. The ‘experimental patient’ is interrogating the ways knowledge is acquired and action is planned within the neuropsychiatric field of practice as well as its therapeutic project. This patient leads the CRC team to carefully interrogate the principles and purpose of its practice. The indeterminacy of its situation created by the permanent association of a biotechnology with a patient provides the grounds for a moral interrogation of the rapid growth of DBS applications.

References

- AGID, Yves, SCHÜPBACH, Michael, GARGIULO, Marcela *et alii* (2006) “Neurosurgery in Parkinson’s disease: the doctor is happy, the patient less so?”, *Journal of Neural Transmission. Supplementa* 70 409-414.
- AMERICAN PSYCHIATRIC ASSOCIATION (2000), *Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition-Text Revision)*. Washington: American Psychiatric Association.
- APPLEBY, Brian S., DUGGAN, Patrick S., REGENBERG, Alan *et alii* (2007) “Psychiatric and neuropsychiatric adverse events associated with deep brain stimulation: A meta-analysis of ten years’ experience”, *Movement Disorders* 22 (12) 1722-1728.

- BAKER, Mary G., KALE, Rajendra and MENKEN, Matthew (2002) "The Wall between Neurology and Psychiatry. Advance in neuroscience indicate it's time to tear it down", *BMJ* 324 (7352) 1468-1469.
- BEJJANI, Paul, DAMIER, Philippe, ARNULF, Isabelle *et alii* (1999) "Transient acute depression induced by high frequency deep brain stimulation", *New England Journal of Medicine* 340 (19) 1476-1480.
- BENABID, Alim Louis, POLLAK, Pierre, LOUVEAU, A. *et alii* (1987) "Combined (thalamotomy and stimulation) stereotactic surgery of the VIM thalamic nucleus for bilateral Parkinson's disease", *Applied Neurophysiology* 50 (1-6) 344-346.
- BRAZIER, Mary Agnes B. (1988) *A History of neurophysiology in the 19th century*. New York: Raven Press.
- BURKHARD, Pierre R., VINGERHOETS, François, BERNEY, Alexandre *et alii* (2004) "Suicide after successful deep brain stimulation for movement disorders", *Neurology* 63 (11) 2170-2172.
- CAMBROSIO, Alberto, KEATING, Peter, SCHLICH, Thomas *et alii* (2006) "Regulatory Objectivity and the Generation and Management of Evidence in Medicine", *Social Science and Medicine* 63 (1) 189-199.
- CLARKE, Adele, SHIM, Janet K., MAMO, Laura *et alii* (2003) "Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine", *American Sociological Review* 68 (2) 161-194.
- DANISH, Shabbar F. and BALTUCH, GORDON, H. (2007) "History of Deep Brain Stimulation", In BALTUCH, Gordon H. and STERN, Matthew (eds.) *Deep Brain Stimulation for Parkinson's Disease*. New York. Informa Healthcare.
- DAROFF, Robert (1990) "The Bridge between Neurology and Psychiatry", *Neurology* 40 (2) 388.
- DIAMOND, Adele and JANKOVIC, Joseph (2005) "The effect of deep brain stimulation on quality of life in movement disorders", *Journal of Neurology, Neurosurgery and Psychiatry* 76 (9) 1188-1193.
- EHRENBERG, Alain (2009) *The Weariness of the Self. Diagnosing the History of Depression in the Contemporary Age*. Montreal: McGill-Queen's University Press.

- EHRENBERG, Alain (2011) "The "social" brain. An epistemological chimera and a sociological fact", In ORTEGA, Francisco and VIDAL, Fernando (eds.) *Neurocultures. Glimpses into an Expanding Universe*. New York/Frankfurt/Berlin. Peter Lang.
- FINGER, Stanley (1994) *Origins of Neuroscience: A History of Explorations into Brain Function*. New York: Oxford University Press.
- GALISON, Peter (1997) *Image and Logic*. Chicago: University of Chicago Press.
- GAUDILLIÈRE, Jean-Paul and LÖWY, Ilana (eds.) (1998) *The Invisible Industrialist. Manufactures and the Production of Scientific Knowledge*. London: Macmillan.
- GISQUET, Elsa (2008) "Cerebral implants and Parkinson's disease: A unique form of biographical disruption?", *Social Science & Medicine* 67 (11) 1847-1851.
- GRABLI, David, MCCAIRN, Kevin, HIRSCH, Etienne *et alii* (2004) "Behavioural disorders induced by external globus pallidus dysfunction in primates: I. Behavioural study", *Brain* 127 (9) 2039-2054.
- HAMANI, Clement, McANDREWS, Mary Pat, COHN, Melanie *et alii* (2008) "Memory Enhancement Induced by Hypothalamic/Fornix Deep Brain Stimulation", *Annals of Neurology* 63 (1) 119-123.
- HOUETO, Jean-Luc, KARACHI, Carine, MALLET, Luc *et alii* (2005) "Tourette's syndrome and deep brain stimulation", *Journal of Neurology, Neurosurgery and Psychiatry* 76 (7) 992-995.
- KANDEL, Eric R. and SQUIRE, Larry R. (2000) "Neuroscience: Breaking Down Scientific Barriers to the Study of Brain and Mind", *Science* 290 (5494) 1113-1120.
- KEATING, Peter and CAMBROSIO, Alberto (2003) *Biomedical Platforms. Realigning the Normal and the Pathological in Late 20th Century Biomedicine*. Cambridge: MIT Press.
- KRACK, Paul, BATIR, Alina, VAN BLERCOM, Nadège *et alii* (2003) "Five-year follow-up of bilateral stimulation of the subthalamic nucleus in advanced Parkinson's disease", *The New England Journal of Medicine* 349 (20) 1925-1934.

- KRINGELBACH, Morten L., JENKINSON, Ned, OWEN, Sarah L.F. *et alii* (2007) "Translational principles of deep brain stimulation", *Nature Reviews Neuroscience* 8 623-635.
- KUSHNER, Howard (1999) *A Cursing Brain? The Histories of Tourette Syndrome*. Cambridge: Harvard University Press.
- LATOUR, Bruno (1992) "The costly ghastly kitchen", In CUNNINGHAM, Andrew and WILLIAMS, Perry (eds.) *The Laboratory Revolution in Medicine*. Cambridge: Cambridge University Press.
- LLOYD, Stephanie and MOREAU, Nicolas (in press) "Becoming 'Normal': Normativity, Ideals and Disorders of Mood and Anxiety", *Medical Anthropology*.
- LOCK, Margaret and GORDON, Deborah (eds.) (1988) *Biomedicine Examined*. Dordrecht: Kluwer Academic Publishers.
- LOCK, Margaret, YOUNG, Alan and CAMBROSIO, Alberto (eds.) (2000) *Living and working with the new medical technologies. Intersections of inquiry*. Cambridge: Cambridge University Press.
- LÖWY, Ilana (1992) "The Strength of Loose Concepts. Boundary Concepts, Federative Experimental Strategies and Disciplinary Growth: the Case of Immunology", *History of Science* 30 (90) 371-396.
- LÖWY, Ilana (1997) *Between bench and bedside. Science, healing and interleukin-2 in a cancer ward*. Cambridge: Harvard University Press.
- LÖWY, Ilana (2000) "The experimental body", In COOTER, Roger and PICKSTONE, John (eds.) *Medicine in the twentieth century*. London: Harwood Academic Publishers.
- MALLET, Luc, MESNAGE, Valérie, HOUETO, Jean-Luc *et alii* (2002) "Compulsions, Parkinson's disease and stimulation", *Lancet* 360 (9342) 1302-1304.
- MALLET, Luc, SCHÜPBACH, Michael, N'DIAYE, Karim *et alii* (2007) "Stimulation of subterritories of the subthalamic nucleus reveals its roles in the integration of the emotional and motor aspects of behaviour", *PNAS* 104 (25) 10661-10666.
- MALLET, Luc, BUOT, Anne, MOUTAUD, Baptiste *et alii* (2008) "Quelles sont les données expérimentales qui justifient l'utilisation de la stimulation cérébrale profonde pour le traitement des

- maladies neuropsychiatriques?”, *Mouvements Neurosciences Biologiques* 1 4-20.
- MALLET, LUC, POLOSAN, Mircea, JAAFARI, Nemat *et alii* (2008) “Subthalamic Nucleus Stimulation in Severe Obsessive-Compulsive Disorder”, *The New England Journal of Medicine* 359 (20) 33-46.
- MARTIN, Joseph B. (2002) “The Integration of Neurology, Psychiatry, and Neuroscience in the 21st Century”, *American Journal of Psychiatry* 159 (5) 695-704.
- MOUTAUD, Baptiste (2008) “C’est un problème neurologique ou psychiatrique?” Anthropologie de la neurostimulation intracrânienne appliquée à des troubles psychiatriques”, In MISSA, Jean-Noël (eds.) *Les maladies Mentales*. Paris. Presses Universitaires de France.
- MOUTAUD, Baptiste (2010) “L’implantation de la recherche clinique à l’hôpital en France: Histoire de la création des centres d’investigation clinique”, *Médecine/Sciences* 26 (8-9) 768-771.
- MOUTAUD, Baptiste (2011) “Are we Receptive to Naturalistic Explanatory Models of our Disease Experience? The applications of Deep Brain Stimulation to Obsessive Compulsive Disorders”, In VAN KEULEN, Ira and PICKERSGILL, Martyn (eds.) *Sociological Reflections on the Neurosciences*. Bingley. Emerald.
- PERLMUTTER, Joel S. and MINK, Jonathan W. (2006) “Deep Brain Stimulation”, *The Annual Review of Neuroscience* 29 (1) 229-527.
- PIES, Ronald (2005) “Why Psychiatry and Neurology Cannot Simply Merge”, *Journal of Neuropsychiatry & Clinical Neurosciences* 17 (3) 304-309.
- PISAPIA, Jared M., HALPERN, Casey H., WILLIAMS, Noel N. *et alii* (2010) “Deep brain stimulation compared with bariatric surgery for the treatment of morbid obesity: a decision analysis study”, *Neurosurgical Focus* 29 (2) E15.
- PRICE, Bruce H., ADAMS, Raymond D. and COYLE, Joseph T. (2000) “Neurology and psychiatry: Closing the great divide”, *Neurology* 55 (4) 602.
- RABÉHARISOA, Vololona (2006) “Vers une nouvelle forme de travail médical? Le cas d’une consultation en psychiatrie génétique de l’autisme”, *Sciences Sociales et Santé* 24 (1) 83-114.

- RABÉHARISOA, Vololona and BOURRET, Pascale (2009) "Staging and Weighting Evidence in Biomedicine: Comparing Clinical Practices in Cancer Genetics and Psychiatric Genetics", *Social Studies of Science* 39 (5) 691-715.
- SCHIFF, Nicholas D. GIACINO, Joseph T., KALMAR, Kathy *et alii* (2007) "Behavioural improvements with thalamic stimulation after severe traumatic brain injury", *Nature* 448 (7153) 600-604.
- SCHWALB, Jason and HAMANI, Clement (2008) "The history and future of deep brain stimulation", *Neurotherapeutics* 5 (1) 3-13.
- SCHÜPBACH, Michael, GARGIULO, Marcela, WELTER, Marie-Laure *et alii* (2006) "Neurosurgery in Parkinson disease. A distressed mind in a repaired body?", *Neurology* 66 (12) 1811-1816.
- TALAN, Jamie (2009) *Deep Brain Stimulation: A New Treatment Shows Promise in the Most Difficult Cases*. Washington: Dana Press.
- WALKER, A. Earl (1957) "Stimulation and ablation: Their role in the history of cerebral physiology", *Journal of Neurophysiology* 20 (4) 435-449.
- WELTER, Marie-Laure, MALLET, Luc, HOUETO, Jean-Luc *et alii* (2008) "Internal Pallidal and Thalamic Stimulation in Patients With Tourette Syndrome", *Archives of Neurology* 65 (7) 952-957.
- WITJAS, Tatiana, BAUNEZ, Christelle, HENRY, Jean-Marc *et alii* (2005) "Addiction in Parkinson's Disease: Impact of Subthalamic Nucleus Deep Brain Stimulation", *Movement Disorder* 20 (8) 1052-1055.
- YUDOFKY, Stuart C. and HALES, Robert E. (2002) "Neuropsychiatry and the Future of Psychiatry and Neurology", *American Journal of Psychiatry* 159 (8) 1261-1264.

'SITING' GENETIC COUNSELLING FOR PRE-SYMPTOMATIC GENETIC TESTING IN AUSTRIA

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Introduction

Genetic reasoning in relation to the explanation of certain medical problems that “run in the family” has a long tradition in Western societies and elsewhere. However, the advent of molecular genetic diagnostics, which became available with the genomic research and biotechnological advances of the early 1990's, has provided the field with a new dimension. For the first time gene mutations which were held as causal factors for the development of so-called “late onset diseases” such as Huntington's disease or familiar breast cancer became diagnosable long in advance of any manifest symptoms. Such “predictive” or “pre-symptomatic” tests, which have been developed for a growing number of diseases linked to hereditary aetiological factors, promise great advances in controlling diseases and prolonging life.

Yet, due to the complex aetiology of many hereditary diseases only a few conditions can be predicted with certainty. And while genetic tests may enable a definite diagnosis at the molecular genetic level for a certain condition, prognostic uncertainty often persists if, when, and how the disease manifests itself in the future. Furthermore, for many conditions there are no preventive or disease alleviating measures available. Thus, patients may be left only with the puzzling facts of their “genetic risk.” Such a situation is further complicated by the sensitive quality of genetic information when considering the issues of “genetic privacy” and “genetic discrimination” (KOLLEK & LEMKE, 2008).

Genetic counselling is supposed to be able to control the complexities of conveying genetic information to clients, protecting them from any unwanted ramifications that come with knowing this information. In the “counselling response” (BOURRET *et alii*, 1998: 130) to tensions involved in gene diagnostics “non-directiveness” and “informed consent” related to the “right to know” and the “right not to know” one’s genetic status have become prominent counselling principles. The notion of non-directiveness (that counselling should help clients to make well-informed, autonomous decisions without directing clients to certain decisions) is part of most any guideline, legal regulation, or bioethical discussion surrounding the implementation of genetic testing and ‘good’ genetic counselling. The underlying assumption is that these principles can safeguard the informed choice and decision-making of autonomous clients (DAMM, 2002). The struggle for such safeguards is the result of the new genetics’ direct dissociation from the heritage of the genetics and eugenic programs in place in countries such as the USA, Sweden, Australia, Japan and Nazi-Germany and Austria since the beginning of the 20th century.

Although the practicality or even desirability of non-directive counselling has been questioned by some commentators (WILLIAMS *et alii*, 2002), the principles involved in the practice are still the “universal norm” in genetic counselling (BURKE & KOLKER 1994). However, as I will argue here, the practices of clinical counselling are also shaped by other ‘logics’, which both complement and conflict with non-directedness and informed consent. Such logics (e.g. consumerism or the imperative of prevention, cf. KONRAD, 2005; KOCH & SVENDSEN, 2005) have been dealt with in the growing body of literature on genetic counselling. However, they have hardly been analysed in terms of their generative capacities to inform particular counselling modes. Moreover, no attempt has been undertaken to map the variety of counselling modes within a specific country, thus failing to make visible the variety found in addressing political, economic, and conceptual interrelatedness along with the general shifts in genetic counselling.

In this paper I will look at how pre-symptomatic genetic testing has become implemented in Austrian counselling services.

I will also examine the impact this has had on the institutional landscape and clinical practices of genetic counselling as well as the ideas surrounding so-called “good counselling.” On the basis of ethnographic fieldwork performed by Monika Lengauer and myself in five Austrian counselling centres between March 2006 and June 2007, I focus on the link between particular counselling modes and their institutional contexts and how counselling practices are shaped by these links. Using a praxeological approach as expounded by social theorist Theodore Schatzki (1996, 2002, 2003) I argue that the specificities of the various counselling modes found in Austria can best be understood as the effects of how counselling practices are “sited,” that is *where* they exit and happen.

The Ethnographic study

Our ethnographic study had two main phases. (1) In a three month explorative phase we gained a general overview of the practice of pre-symptomatic genetic testing and genetic counselling in Austria by conducting 21 expert interviews (mostly with the heads of clinical organisations that are engaged in genetic testing and genetic counselling). (2) The fieldwork phase included the collection of 37 genetic counselling cases which consisted of sessions for genetic testing both for late onset hereditary diseases and for carrier status. The main methods we used were participant observations during the counselling sessions and follow-up interviews with counselees and counsellors. A detailed presentation and analysis of the material can be found in Hadolt & Lengauer (2009).

Social Practices and their sites

Our premise in studying genetic counselling is that the various activities performed in genetic counselling sessions constitute a social practice, that is, “a temporally unfolding and spatially dispersed nexus of doings and sayings” (SCHATZKI, 1996: 89). The

intentional activities of participants are not as central here as are the “orders and dynamics of collective chains of activities” (KNORR CETINA, 2002: 21, my translation). Only as part of a concrete social practice does an activity exist as activity. Simultaneously, the “hanging together” of doings and sayings entails certain arrangements of entities, in and through which social practices unfold. Such entities (in the case of genetic counselling these include counsellors, counsees, their mostly familial attendants, and the various surrounding artefacts such as desks, writing tools, utilities for blood withdrawal, and health records) gain their identities and meanings as part of these arrangements (or “orders”, SCHATZKI, 2002). Practice and order are the two aspects of one and the same “practice-order” (*ibid.*), the inseparable complex of social practice and its arrangement of constitutive entities. From such a perspective genetic counselling is to be understood as a specific practice-order, which is constituted by heterogeneous, performative, and material components that obtain specificity by the hanging together both of components and the practice-order with other such practice-orders.

One form of the interconnectedness of practice-orders refers to what Schatzki calls “site.” As a specific form of context, a site is characterised by the fact that at least one part of the phenomenon of which the site constitutes the context also is an intrinsic part of the site itself. Sites are “contexts of which some of what exists or occurs within them are inherently parts” (SCHATZKI, 2003: 176). *Where* something exists, is “that extended and articulated phenomenon or realm of which it is intrinsically a part. Something’s site in this sense is that phenomenon or realm (if any) as part of which it is or occurs” (SCHATZKI, 2002: 64). A practice-order and its site, thus, are connected via certain activities, normativities, and entities which simultaneously are inherent parts of the practice-order and its site. By way of sites, practice-orders are linked to each other in a particularly strong and intimate way.

Genetic counselling as practice-order exists in various sites (e.g. genetic laboratories, health insurance companies, the patient’s kinship network, biobanks, genetic research organizations, or self-help groups). Particularly important sites are firstly the practice-order-complex of the hospital where genetic counselling usually

takes place. The hospital and genetic counselling share employed medical specialists, computer equipment, consultations rooms, medical records, blood samples of the tested individuals, opening hours, waiting rooms, cleaning schedules, and collected data for research. A second realm of sites, the focus of this paper, concerns the particular disciplinary context in which genetic counsellors and counselling practices are based. In Austria this refers to the medical field of clinical genetics on the one hand and medical fields such as gynaecology, paediatrics, surgery, or oncology on the other.

Genetic diagnostics/counselling in Austria

In contrast to prenatal genetic counselling, available in Austria since the 1970's, postnatal genetic testing and counselling have become more important only in the late 1990's. The growing interest in clinical genetics can be attributed to the growing availability of molecular genetic tests and genetics' general gain of importance in biomedicine and other societal domains (FRANKLIN, 2003). Before the mid 1990's this area was rather marginal, partly due to the historical association of genetics with eugenics and euthanasia during the Nazi regime as well as the fact that a critical working through of this problematic past had been slow (BAADER *et alii*, 2007). This weak institutionalisation of 'classical' clinical genetics left considerable institutional indeterminateness for new types of genetic services to emerge.

In Austria genetic testing and counselling is located within the public health care system, which is financed by a system of compulsory health insurance and state subsidies and in which easy access and state of the art treatment for all is central. Consequently, genetic testing and counselling are paid for mostly by the state in one form or another and thus free of charge for the patient.

Austria is among the few countries in which pre-symptomatic genetic testing and counselling is explicitly regulated by law. The *Gene Technology Law* (*Gentechnikgesetz*), passed in 1994 and amended in 2005, prescribes that laboratories have a special licence for genetic testing, that counselling has to be non-directive,

that counselling has to take place before and after a molecular genetic test, and that patients be handed a letter summarising all important issues discussed during the counselling sessions. In addition, only specialised medical doctors are entitled to work as genetic counsellors for predictive genetic testing. Counsellors can be clinical geneticists, as can be doctors from other medical specialities as long as the genetic condition at issue falls within his/her expertise. Contrary to other countries, there are no 'genetic nurses' or biological geneticists doing counselling. Psychologists are sometimes involved in the process, but only as a kind of helper in special cases where psychological support is provided.

In contrast to countries such as Germany, there are hardly any resident physicians specialised in medical genetics offering genetic testing or counselling. Most pre-symptomatic genetic counselling therefore is provided by counselling centres located at medical university hospitals or other major general hospitals.

Understandings of clinical genetics: 'autonomous' and 'additive'

There are two different ways clinical genetics can be understood and institutionalised in Austria (see table 1).

(1) Human genetics is a distinct area of its own, which may be called *autonomous* human genetics. From this standpoint genetics is understood as a discrete medical discipline, which, similar to pathology, cross-cuts all other medical areas. *Autonomous* medical specialists in human genetics usually undergo specialist training for several years in clinical genetics and claim to have extensive genetic expertise relevant to all other medical areas. Since extensive training in clinical genetics has hardly been available in Austria, many clinical geneticists have been imported from Germany where such training programmes have a much longer tradition. Only since the late 1990's have a few geneticists, graduating from slowly emerging Austrian training programmes, started working as genetic counsellors.

(2) Clinical genetics is *additive* to other medical specialisations, in particular gynaecology, paediatrics, surgery, oncology, dermatology, and neurology. From this point of view genetics

is understood as a part of these areas, and medical specialists, in addition to their main speciality, have extra, albeit limited, expertise in genetics relevant to their main subject. These experts acquired their genetic knowledge either on their own by studying the relevant literature and/or they attended a couple of weekend-courses in general genetics. They usually claim to be the best equipped to handle genetic issues related to their main discipline. The disciplinary areas related to these two forms of clinical genetics constitute important sites for genetic counselling and in consequence significantly shape counselling practices.

Table 1: *autonomous versus additive clinical genetics*

| | <i>autonomous clinical genetics</i> | <i>additive clinical genetics</i> |
|---|---|--|
| medical area of counsellor | medical genetics | gynaecology paediatrics surgery etc. |
| medical focus | generalising (including all genetic diseases) | specialised (focussed on a specific disease) |
| relationship between genetic counselling and medical intervention | separated (counsellor and attending physician are different persons) | integrating (counsellor and attending physician is the same person) |

Currently there are intense political fights going on between proponents of autonomous and additive clinical genetics. The battle is ostensibly fought over the question of which model would be the best for the benefit of clients and thus who should be entitled to provide genetic counselling. However, what is also at stake is the issue of who has the power of definition and who can claim jurisdiction over clinical genetics in Austria.

Institutional landscape of genetic counselling

In Austria there are currently eight major counselling centres for pre-symptomatic testing. Related to the two understandings of clinical genetics we identified three settings of how genetic counselling is put into clinical practice.

The first setting, counselling centres for general medical genetics, corresponds to the *autonomous* form of medical genetics. All such centres are located in major hospitals and are closely connected to laboratories providing genetic testing. The two centres where we did fieldwork were founded in 1996 and 2002 respectively and each of them employs two geneticists (a female and a male physician) who also perform the counselling. In the first centre about 250 genetic consultations are done per year; in the second about 100. In both centres a wide variety of mostly rare and often difficult to diagnose genetic diseases are dealt with. In addition, for most of these diseases no preventive or therapeutic measures are available. It is in this setting where genetic counselling is most 'professionalised' in the sense that special training programmes for counsellors are in place, and guidelines for genetic counselling are formulated and put into practice most explicitly. Counselling sessions often take an hour or more, and clients are required to get an appointment beforehand.

The second setting, specialised outpatient clinics for a small number of hereditary diseases, relates to the *additive* form of medical genetics. Both outpatient clinics included in our study specialise in hereditary tumours, and were founded in 1994 when genetic tests related to these tumours became available. The first centre specialises in hereditary colorectal cancer, in particular familial adenomatous polyposis (FAP), and all counselling sessions (about 130 per year) are performed by a female surgeon. The second outpatient clinic is specialised in familial breast and ovarian cancer. Counselling (about 300 sessions per year) is provided by two female gynaecologists and supplemented by a female clinical psychologist. For both cancer types there exist life-prolonging or life-saving treatment options. In this setting,

genetic consultations are embedded typically in a range of more comprehensive services of care and treatment for the disease.

Finally, we identified a third setting, the counselling outreach clinic for reproductive questions, which combines characteristics of both autonomous and additive medical genetics. The centre in question was founded in 1995, and is located in a major hospital where it is closely associated to the genetic laboratory of the gynaecology department. The genetic consultations (about 200 per year) are performed by a male gynaecologist. As in setting 1 the counsellor has to deal with a wide range of genetic disorders, most of which do not fall into the field of gynaecology. However, since these conditions are discussed in relation to reproductive questions, counsellors and counselees see fit that gynaecologists provide the counselling. He also offers various other gynaecological services such as prenatal diagnostics and abortion.

The disciplinary 'sittings' of counselling practices

Although most of the 37 counselling sessions we studied share procedural features such as taking family history, teaching general genetics and inheritance, and taking blood samples for genetic testing, they differ in other aspects. Two dimensions that are particularly important with regard to their differences are: (1) the range of topics covered in counselling (we call this *range of clarification*, in German *Klärungsreichweite*); all sessions include counselling on medical aspects of the disease, but some consultations include psychosocial questions (such as the client's feelings and coping capacities) or decisions about a future child's destiny. (2) Counselling sessions differ in how counselling is connected to further treatment (*management of being affected*, *Betroffenheitshandhabung*). Whereas *range of clarification* is about the question of *what* needs clarification in counselling sessions, the dimension of *management of being affected* refers to *how* this is done and for *which ends*. This latter dimension is closely related to the sittings of genetic counselling.

In our case material *management of being affected* took on one of two forms. The first is strongly oriented towards genetic

consultation itself, and does not go beyond its organisational boundaries; the main focus lies on making a diagnosis and prognosis, and on discussing these topics with the clients. In being “consultation-focussed,” this first mode may include a discussion on options for prevention or treatment, but it is not closely linked to the treatment itself. The paramount goal on which counselling is focused is the provision of ‘good counselling,’ highly valuing ‘traditional’ counselling principles, and most importantly non-directiveness and informed consent. This logic of consultation goes along with the *autonomous* understanding of clinical genetics. It sites genetic counselling in human genetics as a discrete medical area from which counsellors derive their professional self-understanding as primarily good diagnosticians and counsellors.

In contrast, the second form of *management of being affected* goes beyond the actual genetic consultation, and closely links the counselling process to the treatment process. The main emphasis in this “treatment-extended” mode lies on treatment; the counselling process is intended to provide only the first step in a more comprehensive programme of medical care. In cases which follow this mode of counselling and treatment, they are often performed by one and the same doctor within the same clinical department. Certainly, this mode requires that preventive or therapeutic measures be available for the disease concerned. However, the ultimate goal is the provision of ‘good treatment,’ highly valuing the physical well-being or survival of the patients. This consultative logic is associated with the *additive* understanding of clinical genetics. It sites genetic counselling in treatment-oriented clinical areas such as gynaecology, surgery, or paediatrics. Such sites facilitate the derivation of a counsellors’ professional self-understanding as a good therapist and saver of patients’ lives.

Counselling principles in practice

The specific ‘sittings’ of genetic counselling in disciplinary contexts and the matter of whether counselling is approached as a “consultation-focussed” or “treatment-extended” project have

profound implications on the ways counselling is actually put into practice.

Unfortunately I cannot go into the heterogeneity of counselling and the various 'counselling logics' which we found to inform different modes of counselling (cf. HADOLT & LENGAUER, 2009). However, our data show that despite the fact that all counsellors stress the importance of non-directiveness as their counselling principle, the counselees' possibilities of making choices are rather limited within the realm of actual counselling practice. Counselees only have major choices (having a genetic test done, or learning about test results or not) in situations in which the curative, "treatment-extended" approach does not work; such situations arise either when therapies are not available or when decisions relate directly to the counselee's life-situation (e.g. deciding about whether or not to have a baby), rather than to 'medical' issues in the narrow sense (choosing a treatment option). If preventive or therapeutic measures are available, and even more so when the disease at issue is severe and its predictability high, questions of choice hardly ever come up during genetic consultations; the directive of making well-informed, autonomous decisions as the central attribute of non-directedness is defied. On the contrary, in such situations patients are expected to comply with doctors' advice and opt for the life-saving removal of the rectum or periodic mammographies without much questioning; in most cases they indeed willingly follow the doctors' orders. In addition, the patients are sometimes explicitly encouraged to inform potentially affected relatives about their risk.

Concluding remarks

The proponents of autonomous and additive genetics seek to secure their jurisdiction for hereditary diseases by referring to the notions of autonomous choice on the one hand and prevention on the other. The struggle for topical ownership, thus, is mirrored in conflicting ideas about 'good counselling': autonomous genetics values counselling for its own sake, whereas additive genetics stresses counselling as a first step to effective treatment. Indeed,

even though both kinds of counsellors praise non-directiveness as their counselling principle, non-directive counselling is rather limited in practice, particularly when treatment is available.

The additive understanding of genetics took its departure from more traditional practices of biomedical care, which are based on the “imperative of prevention” (KOCH & SVENDSEN, 2005) as the paramount normative orientation of the medical encounter. Additive genetics stands for an incremental change of a health service which incorporated the new knowledge techniques of pre-symptomatic testing as a more sophisticated diagnostic and prognostic means. It did so without changing much of the underlying ethos of the ‘medical fix’ of medical problems. It can be expected that the additive type of genetic service becomes even more prominent when treatment becomes available for more hereditary diseases (this may be particularly promising in the field of cancer genetics).

The relative success of the *additive* model of genetic counselling puts the ‘classical’ model of genetic counselling under pressure. Even though *autonomous* clinical geneticists still defend their approach, they try to modify their services and focus more on post-counselling care. Some counselling centres do so by collaborating more closely with other medical care oriented clinical departments or by experimenting with models of co-counselling, in which geneticists visit other medical departments and attend consultations. However, what these developments point at is the medicalisation of genetics, rather than the geneticization of medicine, as is sometimes stated in the literature (LIPPMAN, 1992). This tendency also shows that the ways of where and how medical services are sited are indeed important for the question of how and with which effects the models are put into practice.

References

- BAADER, Gerhard, HOFER, Veronika & MAYER, Thomas (2007). *Eugenik in Österreich: Biopolitische Strukturen von 1900- 1945*. Wien: Czernin.

- BOURRET, Pascale, KOCH, Lene & STEMERDING, Dirk (1998). DNA Diagnosis and the Emergence of Cancer-Genetic Services in European Health Care. In: Wheale, Peter, Schomberg René von & Glasner Peter (eds.) *The Social Management of Genetic Engineering*. Aldershot u.a.: Ashgate.
- BURKE, Meredith & KOLKER, Aliza (1994) "Directiveness in Prenatal Genetic Counseling", *Women & Health* 22(2): 31 - 53.
- DAMM, Reinhard (2002) "Imperfekte Autonomie und Neopaternalismus", *Medizinrecht* 8: 375-387.
- FRANKLIN, Sarah (2003) "Re-thinking nature-culture: Anthropology and the new genetics", *Anthropological Theory* 3(1): 65-85.
- HADOLT, Bernhard & LENGAUER, Monika. (2009) *Genetische Beratung in der Praxis: Herausforderungen bei präsymptomatischer Gendiagnostik am Beispiel Österreichs*. Frankfurt/Main: Campus.
- KNORR CETINA, Karin (2002[1999]). *Wissenskulturen: Ein Vergleich naturwissenschaftlicher Wissensformen*. Frankfurt/Main: Suhrkamp.
- KOCH, Lene & SVENDSEN, Mette Nordahl (2005) "Providing solutions-defining problems: The imperative of disease prevention in genetic counselling", *Social Science & Medicine* 60(4): 823-832.
- KOLLEK, Regine & Thomas LEMKE (2008). *Der medizinische Blick in die Zukunft: Gesellschaftliche Implikationen prädiktiver Gentests*. Frankfurt/M.: Campus.
- KONRAD, Monica (2005) *Narrating the New Predictive Genetics: Ethics, Ethnography, and Science*. Cambridge: Cambridge University Press.
- LIPPMAN, Abey (1992) "Led (astray) by genetic maps: The cartography of the human genome and health care", *Social Science and Medicine* 35(12): 1469-1476.
- SCHATZKI, Theodore R. (1996) *Social Practices: A Wittgensteinian Approach to Human Activity and the Social*. Cambridge: Cambridge Univ. Press.
- SCHATZKI, Theodore R. (2002) *The Site of the Social: A Philosophical Account of the Constitution of Social Life and Change*. University Park, Pa.: Pennsylvania State Univ. Press.
- SCHATZKI, Theodore R. (2003) "A new societist social ontology", *Philosophy of the Social Sciences* 33(2): 174-202.

- WILLIAMS, Clare, ALDERSON, Priscilla & FARSIDES, Bobbie (2002) "Is nondirectiveness possible within the context of antenatal screening and testing?" *Social Science & Medicine* 54(3): 339-347.

CAN BIOETHICS EMBRACE DIVERSITY?

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Introduction

The clinical setting is a social space where multiple values come into play. These values can be significantly diverse, following one's background, whether professional, ethnic, religious, class or gender-based. The same can be extended to ethical principles that guide clinical practice, in that these principles are socially, culturally, historically constituted within a given context. How do these values meet within cosmopolitan clinical settings? Inspired by fieldwork in hospital environments and beyond, this paper questions the domain of bioethics and its capacity to embrace diversity. My fieldwork broadly focuses upon the social space of the clinical setting where expert and lay knowledge, values and norms are negotiated in an on-going basis within different localities. Consequently, I have come to question this same negotiation in the world of biomedical ethics.

The hospital environment is permeated by a number of phenomena, notably the social, cultural, religious diversity of its clientele (which mirrors the western cities where the fieldwork was conducted). Medicine's technological progress¹ as well as the expansion of physician subspecialties, multiple trainees and other health care professionals that may be related to a given patient and the never ending training expectations and opportunities of specialized medicine are also part and parcel of today's hospital setting. New ethical questions are asked daily and physicians struggle to find answers to these questions that go beyond their

¹ For further readings on this topic, see LOCK and NGUYEN, 2010; FORTIN *et alii*, 2008; MOULIN, 2004; SAINSAULIEU, 2003; LOCK, 2002.

biomedical expertise; surrounding issues of high-risk pregnancies and prenatal diagnosis, premature births and life support systems, chronic/acute disease cycles and again, life support systems in intensive care units. When does one proceed with treatment, or when to stop? When is it a quality of life issue or that of the best interest of the patient...

Each day I find myself looking deeper into the extremely subtle distinction (if a distinction even exists) between the personal values of physicians, morals and a given ethical stance. These ethical positions (or recommendations) take on the power of moral laws (or norms) in the space of the clinic, since physicians will refer to them in order to legitimize their stance regarding a certain medical practice or therapeutic orientation. How do personal values and morals interact within ethics? Whose values are to become normative within the space of the clinic? And can bioethics (and clinical ethics) embrace such diversity?

In the following pages, questions and answers will alternate in order to sketch out, perhaps in an insufficient manner (my apologies to the reader), a quest to better understand how morals and ethics intertwine in the space of the clinic. By doing so, we hope to advance the relationship between anthropology and the field of ethics. Case examples and field data will help elicit the intricate link between individual values and norms of practice. The discussion will further attempt to set the premise for a plural normativity.

When values become norms

CASE EXAMPLE 1:

The termination of a pregnancy in the third term is a clinical issue for tertiary care institutions as they have the degree of specialization required for such procedures. In Quebec (as in the rest of Canada), there is no specific civil law governing this practice. In other words, the Canadian Criminal Code does not in any way limit this practice (as of the 1988 R. v. Morgentaler ruling). Voluntary termination of a pregnancy is legally available

to any woman if she desires, up to a certain number of weeks (12, 14 or 16 weeks) according to the medical institution (hospital or clinic) and the facilities available. In this specific case example, abortions are performed within the first 20 weeks of pregnancy regardless of the patient's reasons for making this decision. Women asking for an abortion at a later period (between 20 and 22 weeks of pregnancy) will be referred to other health institutions and eventually, to specialized clinics in the United States (post 22 weeks of amenorrhea), unless the reasons for termination are due to a medical condition. Late terminations of pregnancy [LTP] (after 23 or 24 weeks) will be performed only if a severe medical condition is at hand, notably foetus abnormality (COMITÉ, 2007; COLLÈGE des MÉDECINS du QUÉBEC, 2004).²

The viability of the foetus being currently established at 24 week of life in utero, is LTD at odds with the medical professional code of ethics or medical morals?³ While medical consensus is more easily achieved when "clear cut" severe abnormalities are foreseen (such as severe neurological impairment that would lead to death of the newborn), many pathologies identified through prenatal testing (such as trisomy 21 and spin-bifida) are not lethal, and subject to earlier pregnancy termination. When these latter situations are diagnosed or become 'an issue' in the third term, medical and moral boundaries are blurred. Medical uncertainty in regards to the effectiveness of prognostication is also put into question. And finally, is practicing LTP against the hospital's mandate of protecting mother *and* child health or, on the contrary, is it not part of this mandate in light of the biomedical expertise of tertiary health institutions?

² In line with the Canadian Pediatric Society and the Society of Obstetricians and Gynaecologist of Canada recommendations.

³ The medical community's preoccupations included other issues pertaining to the potential trivialization of the procedure and the possible increase in LTP requests, to eugenic drifts or to LTP becoming an answer to the insufficient availability of health and social services for disabled children (COMITÉ, 2007).

As for personal morals, Pro-life/Pro-Choice debates permeate termination of pregnancy at all stages.⁴ They mirror a society that remains polarized on these issues, as are those people working in the clinical environment. In this way, clinicians are members of the society in which they work and live, a potent reminder of the indivisible link between the city (*la localit *) and the hospital. However, unlike the 'mere' citizen, the individual values of doctors can come to serve as norms of care. In light of professional autonomy, physicians can refuse to perform LTP; they then have the responsibility to refer the patient to another doctor. Others may recognize the practice as legitimate if the foetus has been given a bleak prognosis. But when does an abnormality become severe? For whom?

An advisory report published by the local hospital bioethics committee (COMIT , 2007) specifically addressed the question of LTP motivated by important foetal abnormalities after the viability threshold and offered guidelines should the late-term termination be put into practice. Despite all the nuances (and perhaps beyond its goals), the report fell silent on issues pertaining to the threshold of viability itself; notions of first, second and third-terms not being a natural given and are blurred as technology evolves. With these ambiguities in defining the borders between terms and the viability threshold, how then is it possible to reconcile such norms of practice with the fact that voluntary termination is accessible to women in Canada?⁵

Notwithstanding the particularities of an abortion in the third-term as well as the moral challenges entailed by the medical procedure,⁶ are physicians' individual ethics (Pro-choice or Pro-

⁴ These positions can be defined in the following manner: Pro-choice is the right of the mother to decide for her own best interest and that of her unborn child; Pro-life argues that the foetus has an inalienable right to live (in this case, advocated by the doctor).

⁵ One could argue that today's third term specificities will, in time, be extended to earlier stages of pregnancy as medicine evolves.

⁶ These challenges are related to the potential viability of the foetus (in the third term) at the time of the abortion and the medical proc d res entailed.

life) subordinated to a medical issue (and the needs of the patient) that requires their specific expertise? And what is to be said when a foetal abnormality is disclosed? What about when an abortion is highly recommended but the mother wishes to go through with the pregnancy? Or when end of treatment is strongly advised by the health care team but the family wishes to continue aggressive treatment? Or, that the family wants to withdraw treatment and the team wishes to pursue? Can severe neurological impairment justify withdrawal of life support systems? When opinions drastically differ, how can we move forward? Whose norm is to prevail? When, and why?

CASE EXAMPLE 2:

In an ongoing study on religious pluralism in the social space of the clinic (FORTIN & al, 2008-2012) it was interesting to observe how individual clinician's religious backgrounds brought them to consider very differently one or another stances taken by a mother and her spouse in high risk pregnancies or in neonatal contexts (FORTIN & Le GALL, forthcoming). If believed to be religiously-driven decisions, non-believing practitioners would challenge these decisions, if they were in contradiction to expert recommendations. Rather, religiously inclined physicians would acknowledge the individuals' rights to their beliefs. Amongst practitioners, these differences could lead to conflict in regards to what treatment paths to follow and in particular with recurrent end of life issues.

In the recent Québec Commission on euthanasia (*Mourir dans la dignité*), it was interesting to see at the end of the first day's hearing, how an array of citizens (often patients' families) and physicians had basically two different perspectives. A majority of laypersons called for the patient's liberty of 'choice' in the matter and all physicians heard on that given day were clearly against it (MONTPETTIT, 2010).

Clinicians (whether doctors or nurses) often question the validity of an invasive procedure. However, there is no unanimous agreement as to what constitutes an invasive procedure (according

to different subspecialties or to different individuals); furthermore, at what point does a procedure become invasive within a community of practice (JAY *et alii*, 2010) such as hematology-oncology, intensive or neonatal care and obstetrics. And how could this question (with all its possible answers) become a norm of practice and under what circumstances? Clearly the primacy of the patient's well-being, or "good" (*le bien*) of the patient, which constitutes the *locus ethicus* of the relationship between the caregiver and the patient, is a shared core value. Nevertheless this notion of the good of the patient takes on different meanings in the specifics of a given unit, an area of expertise, the concerned individuals (whether physicians, nurses, families) and their different social paths.

To quote Edmund Pellegrino⁷ (2004: 3): "Who does the physician serve – the good of the patient, the success of the team that pays his salary, or his own infatuation with athletic success?" Or in the words of another physician "it's not about me, it's about my patient" (FORTIN & al., 2005-2011). But this conception of the medical 'self' is not innate. It comes from an individual assessment or conception of practice that develops over the course of a lifetime and training experiences. For Le Blanc (2002: 75), the "conflict of medicines" (*le conflit des médecines*) arises when science, with its powerful influence upon the practice of medicine, comes to establish norms of practice, not in relation to the "living subject" or the "suffering subject", but rather in favour of the technical and medical possibilities.

Pandora's Box: Ethics, Norms, Values and Diversity

Much has been said about medical knowledge turned into normative values (LOCK & NGUYEN, 2010; BOUCHAYER *et alii*, 2004; LE BLANC, 2002). My aim is to further examine individual personal

⁷ Edmund Pellegrino is Professor Emeritus of Medicine and Medical Ethics at the Center for Clinical Medical Ethics, Georgetown University Medical Center. He is also Chairman of the President's Council on Bioethics in Washington, D.C.

values that have been transformed into norms and legitimized by the practice of ethics in the context of medical care. In other words, how medical knowledge and physicians' values and practices are intertwined and establish a "norm frame" within the hospital?

Witnessing the makeup of clinical ethics units (which differ from bioethics committees): in my case example, the unit is composed entirely of medical doctors (with the exception of one nurse) who follow a process of dialogue, discussion and consultation with care-giving teams. Yet this dialogue remains within the frame of medicine—undoubtedly recalling Foucault's notions of biopower and governmentality (2004). Is medicine the only discipline that can inhabit the field of "applied" health?

While bioethics is meant to be an interdisciplinary reflection on the relationship to "the living" and the humanization of medical education and practice (JOBIN, 2003; DOUCET, 2002; ROY, 1995; POTTER, 1975), clinical ethics falls within the realm of the clinic itself, at the heart of concrete situations involving the relationships between patients and doctors and the decisions that are constantly involved in caregiving. As for the relationship between morals and ethics, there is no unanimous agreement (RICOEUR, 2001). In the collective imagination, according to Sicard (2009: 6)⁸, morals are normative, developed through strong religious or cultural references, and founded upon a 'principal' tradition whereas the ethics are dynamic and secular, and in constant renewal. The latter are a site of resolution of conflicts of values (MASSÉ, 2003). Some would distinguish morals from bioethics (notably SICARD, 2009: 14) while others see a close relationship between the two (see BOURGEAULT, 2004). The order of norms would then be closely linked to that of values (BOUCHAYER and al., 2004). Yet Ricoeur (2001) goes further as he states that fundamental ethics (a previous order of ethics) are shaped on the horizon of a (local) morality, which in turn gives way to applied ethics (a posterior order of ethics). Morals and their derived norms (upstream morals) nurture bioethics (downstream morals) in a context of

⁸ Didier Sicard, Professor Emeritus of Medicine at l'Université Paris Descartes, was the president of the National Ethics Advisory Committee (France) between 1999 and 2008.

suffering. This suffering can never be ignored, as it is the basis of the relationship between caregiver and patient.⁹ That being said, the case in point is more in line with the idea that the moral order is self-referential (RICOEUR, 2001: 58).

The close relationship between values and norms in the ethical space comes into question, especially when this space is dominated by a single discipline. With its hierarchical top-down structure according to expertise-subspecialty and individual status (staff position, seniority), medicine is both judge and judged in the context of the clinical space. Also, without making assumptions about the homogeneity of professional cultures and the individuals that make them up, the fact remains that depending upon the area (*localité*) these environments they will be more or less diverse. For example, the hospital units I have studied in three cosmopolitan Canadian cities show a marked predominance of Caucasian doctors, from Western majority groups¹⁰ while these cities have an immigrant population ranging between 31% and 49% from an array of countries (particularly so in Montreal). When we take into account the criteria and modes of selection of medical students in Canada, we see that only students with a truly exceptional academic record can apply.¹¹ Without being exclusive to privileged environments, the fact remains that this mode of selection favours students from certain social backgrounds above others; social backgrounds that are unequally representative of the heterogeneity of these cosmopolitan areas.

And what about diversity? How does the “norm frame” within the hospital acknowledge social, cultural, and religious diversity

⁹ On the specifics of the physician/patient relation see MOL, 2008; FAINZANG, 2006; CARNEVALE and BIBEAU, 2007; SAILLANT and GAGNON, 1999.

¹⁰ The physicians are mainly: Quebecois of French Canadian origin and Francophone European migrants in Montreal (where 31% of the population was born outside of Canada); Canadians of British descent and [white] migrants from various British ex-colonies in Vancouver (which has a 46% immigrant population) and in Toronto (49% immigrant population).

¹¹ This is a difference from the French system, for example, which is more inclusive at the beginning of the medical education program and which, after exams, eliminates candidates who do not meet the program's demands.

is a daily challenge, given that diversity is in itself acknowledged. Indeed, my research¹² draws a very different picture of how plurality is taken into account in the clinical space (FORTIN, forthcoming). For some, it does not exist, because all are equal in the area of health care. “In terms of how you practice, I don’t think it changes things other than that you might need an interpreter” (Staff physician). Observations and interview data are quite revealing of the differences between practice and discourse. Universal values of ‘respect’, ‘openness to the other’ and ‘shared humanity in the space of the clinic’ give way to very biased/prejudicial statements when family and healthcare providers differ in opinion or on the course of treatment. The patient and her or his family becomes the Other when conflict arises between the patient, family or doctor in therapeutic situations that involve (key) notions of life, quality of life, or death. Culture becomes the explanation *par excellence* of the parents’ *non-compliance* to the plan of care, and for their incomprehension of medical words or concepts.

If the family’s refusing to let go, you know I start to give them deadlines, I get other people involved to talk to them, potentially people from their own cultural background. For example, if they’re South Asian, it’s someone, a South Asian medical figure or nurse to talk to them and try to explain it to them and then just start setting some deadlines. [Staff physician]

For others, there is the recognition of unequal relationships within the clinic–majority–minority relationships in which players’ knowledge and skills, and the recognition of these, are employed to differing extents.

In ICU, one is dealing of course with quality of life and value judgments about the worth of life in certain situations, which are different, based on one’s upbringing. And so, one tries to assume that the information that you provide will be helpful based on people’s upbringing. And since you don’t have insight necessarily into that, into other people’s beliefs and upbringing, then you might get it wrong, I know you get it wrong. [Staff physician]

Or the following:

¹² See in particular Fortin, (2006, 2008) and Fortin & Carle (2008).

[...] with all of these political correct things, you can't talk about it. ... but everybody (I'm trying to talk about it)... everybody has the same feel, you know... you get a Punjabi family and you know they're gonna have a large, big extended family to visit. We have a two person at the bedside rule and it's ubiquitous how the staff respond to that. And I think that in that you lose the family, you lose the fact that you know, here is the kid, you know, they don't get treated the same all the time. As with the Punjabi speaking guys that haven't necessarily westernized, we have two sort of distinct sets of Chinese populations. We have the very rich, and then we have the working poor. And the working poor tend to be very westernized and congenial and everything else and the very rich don't necessarily have the same interests or whatever so. I find there is a lot, people know what to say to... in terms of being politically correct but they are certainly some of these families will get treated differently. And especially if language is a barrier. Or especially if people feel that they haven't assimilated to the Canadian sort of way. But that's just human nature. [Clinical assistant]

And finally, social, cultural and religious diversity is not seen, by many, as having a bearing on medical practice, which is in this perspective, "evidence-based" knowledge. Pluralistic issues or the 'care concern' would rather be and often are relegated to the nursing field.

Pluralism is not an issue in my practice. Perhaps I'm mistaken. Some of my colleagues who are of a different ethnic background tell me 'it's important to know your patients religious beliefs, to better understand how he/she thinks, what they believe'. But I don't want to know [...] Sure sometimes they [immigrant patients] don't understand. In general, I try to make them repeat what I say. [Staff physician]

And in a conflicting situation with the same physician, where a mother clearly did not comply with this physician's recommendations he states:

Madam, you can think what you want, you can say what you want, it is written here. If you don't follow what I say, your child will die. [Staff physician]

The Premise of a Plural Normativity

Bourgeault (2004) resituates ethics in the context of a majority-minority relationship that shapes the norm, with the majority group

as the referent. In turn, this brings into question the recognition of expert and lay knowledge (*savoirs*) in the clinical encounter. When does a termination of a pregnancy become acceptable, and for what reasons? Who can decide what is acceptable or not, a nurse, a mother, a social worker? Do they all have a say in the decision-making process? Let's say a (Muslim) mother wishes to go ahead with a pregnancy even though it is clear that the baby will not survive. Is she making the decision as a free agent, or do "cultural models" (and gender issues) weigh upon her choices? Which choices are legitimate and according to whom? What about when physicians differ in opinion? And what happens when nurses have difficulties going ahead with a care plan that runs contrary to their ethical principles of practice?

A Muslim mother gives birth to a very sick newborn. The bleak diagnosis and prognosis would, for many, have resulted in a third-term abortion. This family wanted to go through with the pregnancy and wished for aggressive treatment for the newborn. The father is happy, this is his first son. Physicians (as well as nurses) differ on what course of treatment should be taken: aggressive or palliative. One physician (highly ranked within the hospital hierarchy) takes upon himself to decide. After many weeks, many still feel uncomfortable with the decision and wonder how much the family really understood about how the situation evolved.

Cognet (2007:58) proposes an ethical stance of otherness, premised essentially on the recognition that the other carries principles, just as we do ourselves; principles that we may confront at some point in time. Such a position eliminates the pretence of knowing what is best for the other in terms of health and well-being, while allowing space for the examination of the different values that underlie his or her principles and our own. "This does not imply simply floundering in a naïve vision of cultural relativism, but rather indicates a wish that the confrontation of differing principles will call into question the prejudices

that underlie them, the absurdities they uphold and the social inequalities they create.”¹³

The question of cultural relativism has caused a lot of ink to flow like that of universal ethics. Some (in particular, TURNER, 2003) regret the lack of normative models and theories that can encompass the challenges of moral debates in social contexts that are both multi-ethnic and multi-faith, while underlining the fact that even the most homogenous places are not without their conflicts of norms and values. Massé (2009) reiterates the existence of numerous local moralities that have been culturally and historically constructed, moralities woven together with issues that are often universal (good, evil) but played out differently according to the context. The anthropological approach, and its intimate relationship to the field, plays (or can play) a significant role¹⁴ in linking, within the framework of a study of clinical spaces (for example), a micro-sociology (observable relationships and practices) with macro-social contexts (such as majority-minority relations, political, economic, and historical aspects) and meso-social structures (such as communities of practice and local institutional challenges). This approach allows us to embody and give voice to the challenges that arise as a result of the diversity of norms and values within specific clinical situations, and thus to document the ways in which they play out according to the different people involved. Documenting these perspectives and how they are managed contributes to the foundation of a plural normativity. In this regard, while research and analysis are still in progress (FORTIN & al, 2008-2011; 2005-2011), studying “core

¹³ Our translation.

¹⁴ Massé (2009: 26) refines this role by distinguishing an anthropology of morality – which would seek to identify who defines what is moral, with a focus on the analysis of the social distribution of what is prohibited, of responsibilities and of the application of moral rules in various social categories – from an anthropology of ethics – where there would be more attention given to the day-to-day expression of morals, to how these morals are managed, negotiated and to resistance to moral norms. In a broader sense, Lock (2005: 445) states that “all anthropology worthy of the name” would put aside moral judgment in favor of an analysis of the positions and stated activities of the people concerned.

events” where life decisions are involved gives us privileged access to the norms and values that underscore clinical practice.

By way of Conclusion

The “medicalization of health” or the classical biomedical approach, based on pathology, is not a point of conflict for the migrants I have encountered over the course of my fieldwork, from high-risk pregnancies, premature births and to end of life situations. Medicalization and the technology of specialized hospitals (tertiary care centres) are seen as an important resource in local society. Biomedical knowledge is generally sought out and hardly negotiated. When there is a negotiation, without it being a rejection of the prevailing or dominant biomedical perspective, it indicates a convergence of values and the search for an arena where the triad (caregiver-patient-family) can develop. In contrast, when there is a divergence from the biomedical norm, culture and religion become the explicative model, to the detriment of a reflection on the sharing of knowledge, the needs put forward, which remain misunderstood or unheard.

Beyond the immigrant and non-immigrant aspect, notions of diversity and of a plural society propels us to reconsider the clinical localities intersected by gender relations, age relations, pluralities of religion, social backgrounds, and ethnicity that have been historically and politically established. Healthcare providers and families, similar to the members of bioethics or clinical ethics committees are active members in these environments, and carriers of these norms and values that are also created by these environments and their own individual backgrounds. Differently than parents and the society ‘at large’; however, physicians are in a position to influence the norms within the clinical space in terms of their own values.

Similarly, a clinical ethics unit headed by medical professionals is not without normative shifts, despite its desire for all ethical positions to be closely related to the daily challenges encountered by clinicians. Ethics or ethical sensitivity does not inherently imply a pluralist perspective that can embrace diversity – even

when this diversity is narrowly conceived as ethnic and religious diversity. In this way, does ethical reflection involve a distinct body of knowledge or is it not rather a pluralistic process, a pooling together of different points of view that, by their convergence, allow us to see new ways forward?

The emergence of a plural normativity is conditional upon a true interdisciplinarity within the field of health, and in regards to ethics in particular. The negotiation of perspectives (and even conflicts) is in itself a key aspect of an open normative space. The absence of this negotiation is to be feared, not because it suggests the absence of difference/divergences in values, but rather because it is indicative of the solidification of impervious boundaries.

Norms and values are contextual, historical, and cultural. They evolve, they move and they resist all attempts at dichotomization between people from here and elsewhere. The local and the global meet head-on in the space of the clinic and, like local societies, they are pervious to human diversity.

References:

- BOUCHAYER, Françoise, CRESSON, Geneviève, PENNEC, Simone, SCHWEYER, François-Xavier (eds.) (2004) *Normes et valeurs dans le champ de la santé*. Rennes: Éditions ENSP.
- BOURGEAULT, Guy (2004) *Ethiques: dit et non-dit, contredit, interdit*. Montréal: Les Presses de l'Université de Montréal.
- CARNEVALE, Franco and BIBEAU, Gilles (2007) "Which Child Will Live or Die in France: Examining Physician Responsibility for Critical Ill Children", *Anthropology & Medicine* 14:125-37.
- COGNET, Marguerite (2007) "Au nom de la culture: le recours à la culture dans la santé": 39-63, In COGNET, Marguerite and MONTGOMERY, Catherine (dir.), *Éthique de l'altérité. La question de la culture dans le champ de la santé et des services sociaux*. Québec : Les presses de l'Université Laval.
- COLLÈGE DES MÉDECINS DU QUÉBEC (2004) *L'interruption volontaire de grossesse*. Lignes directrices. Montréal: Collège des médecins du Québec.

- COMITÉ DE BIOÉTHIQUE DU CHU SAINTE-JUSTINE (2007) *Interruption de grossesse du troisième trimestre pour anomalie fœtale*. Montréal: Éditions du CHU Sainte-Justine.
- DOUCET, Hubert (2002) "L'interdisciplinarité en bioéthique : Une pratique encore mal définie méthodologiquement": 161-168, In GÉLINEAU, Lucie (dir), *L'interdisciplinarité et la recherche sociale appliquée. Réflexions sur des expériences en cours*. Université Laval, Université de Montréal, Chaire d'Étude Claire-Bonenfant sur la condition des femmes, <http://www.fas.umontreal.ca/sha/recherche/publications/>.
- FAINZANG, Sylvie (2006). *La relation médecins-malades: information et mensonge*. Paris. Presses Universitaire de France.
- FOUCAULT, Michel (2004). "Leçon du 11 janvier 1978": 3-29, *Sécurité, Territoire, Population. Cours au Collège de France, 1977-1978*. Paris: Gallimard Seuil.
- FORTIN, Sylvie (2008) "The Pediatric Clinic as Negotiated Social Space" *Anthropology & Medicine* 15:175-87.
- FORTIN, Sylvie (2006) "Urban Diversity and the Space of the Clinic. Or when Medicine looks at Culture..." *Medische Anthropologie* 18 (2): 365-385.
- FORTIN, Sylvie (*forthcoming*) Conflits et reconnaissance dans l'espace clinique. Les pratiques cliniques en contexte pluraliste. *Anthropologie et Société*.
- FORTIN, Sylvie and LE GALL Josiane (*forthcoming*) "Période périnatale et migration: quelques enjeux pour la pratique infirmière", In DE MONTIGNY, Francine, DEVAULT, Annie and GERVAIS, Christine. (eds), *À la rencontre des parents. Pratiques professionnelles novatrices à l'égard des parents et de leurs enfants*, Montréal :Éditions Chenelière.
- FORTIN, Sylvie and CARLE, Marie Eve (2007). "Santé et pluralisme. Vers un nécessaire repositionnement de la culture dans l'espace clinique" *Bulletin de l'ARIC (Association pour la recherche interculturelle)* 45: 5-19. <http://www.unifr.ch/ipg/sitecrt/ARIC/Publications/Bulletin/bulletin.htm>
- FORTIN, Sylvie, BIBEAU, Gilles, LAUDY, Danielle, CARNEVALE, Franco, ALVAREZ, Fernando, DUVAL, Michel and GAGNON, France (2005-2011) *Clinical Hospital Practice and Urban Diversity. Ongoing study funded by the Canadian Institutes of Health Research*.

- FORTIN, Sylvie, LE GALL, Josiane, BIBEAU, Gilles, PAYOT, Antoine, CARNEVALE, Franco, AUDIBERT, François (2008-2011) Access to perinatal health services by recent migrant Muslim families: reconciling knowledge and health care practices. *Ongoing study funded by the Canadian Institutes of Health Research*.
- JAY, Chrystal, EGAN, Tony, SMITH-HAN, Kelby (2010) "Communities of clinical practice and normalising technologies of self: Learning to fit in on the surgical ward" *Anthropology & Medicine* 17 (1): 59-73.
- JOBIN, Guy (2003) "La normativité de la bioéthique : sa structure et son développement": 11-22. In HERVÉ, Christian, KNOPPERS, Bartha Maria, MOLINARI, Patrick A. and MOUTEL, Grégoire (dir.). *Éthique médicale, bioéthique et normativités*. Paris: Dalloz.
- LE BLANC, Guillaume. (2002) "Le conflit des médecines" *Esprit* 284: 71-80.
- LOCK, Margaret (2005) "Anthropologie médicale: pistes d'avenir": 439-467, In SAILLANT, Francine and GENEST, Serge (dir.). *Anthropologie médicale. Ancrages locaux, défis globaux*. Québec : Les presses de l'Université Laval.
- LOCK, Margaret (2002) "Medical knowledge and body politics": 190-208, In Mac Clancy Jeremy (ed.). *Exotic No More. Anthropology on the Front Lines*. Chicago: Chicago University Press.
- LOCK, Margaret and NGUYEN, Vinh-Kim (2010) "The Normal Body": 32-56, In *An Anthropology of Biomedicine*. West Sussex: Wiley-Blackwell.
- MASSÉ, Raymond (2009) "Anthropologie des moralités et de l'éthique. Essai de définitions" *Anthropologie et sociétés* 33 (3): 21-42.
- MASSÉ, Raymond (2003) *Éthique et santé publique. Enjeux, valeurs, et normativités*. Québec: Presses de l'Université Laval.
- MOL, Annemarie (2008) *The Logic of Care. Health and the Problem of Patient Choice*. London & New York: Routledge.
- MONTPETIT, Caroline (2010) "Mourir dans la dignité: des témoignages bouleversants – Confusion dans les débats sur l'euthanasie" *Le Devoir* 8 septembre 2010.
- MOULIN, Anne-Marie (2004) "Ordre et désordre dans le champ de la santé": 19-36, In BOUCHAYER, Françoise, CRESSON, Geneviève,

- PENNEC, Simone, SCHWEYER, François-Xavier (eds). *Normes et valeurs dans le champ de la santé*. Rennes: Éditions ENSP.
- PELLEGRINO, Edmund (2003) "From Medical Ethics to a Moral Philosophy of the Professions": 3-15, WALTER, Jennifer K. and KLEIN, Eran P. (eds), *The Story of Bioethics*. Washington, D.C.: Georgetown University Press.
- POTTER, Van Rensselaer (1975) "Humility with Responsibility – A Bioethic for Oncologists" *Cancer Research* 35: 2297.
- RICOEUR, Paul (2001) "De la morale à l'éthique et aux éthiques" *Le Juste II*. Paris: Esprit: 55-68.
- ROY, David, WILLIAMS John, DICKENS Bernard & BEAUDOIN Jean-Louis (1995) *La bioéthique. Ses fondements et ses controverses*. Bruxelles/Montréal: De Boeck/ERPI.
- SAILLANT, Francine and GAGNON, Éric (1999) "Vers une anthropologie des soins" *Anthropologie et Sociétés* 23 (2): 5-14.
- SAINSAULIEU, Ivan (2003) *Le malaise des soignants: le travail sous pression à l'hôpital*. Paris, l'Harmattan.
- SICARD, Didier (2009) *L'Éthique médicale et la bioéthique*. Paris: Presses Universitaires de France.
- TURNER, Leigh (2003) "Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings" *Health Care Analysis* 11: 99-117.

ABSTRACTS

Mette Bech RISØR: *The process of symptomization. Clinical encounters with Functional Disorders*

In medical anthropological research on manifestations of illness and the relationship between patient and healer, symptom presentation is often a crucial focus but the symptom as such is seldom taken as the point of departure. Based on a field study of patients with functional disorder this paper explores how bodily signs become symptoms and how they are interpreted in clinical settings. The paper draws on inspiration from Latour and Appadurai to illustrate a process of symptomization.

Sylvie FAINZANG: *From self-diagnosis to self-medication: constructing or identifying symptoms*

On what basis does a bodily sign become a symptom for the subject and in which conditions does he/she decide to self-medicate when confronted with it? We will see that, in self-medication (which concerns more than just benign symptoms), whereas the distinction in medical semiology between subjective and objective signs is inappropriate here, a relevant distinction is to be made between symptoms with an absolute or those with a relative value, as this entails different practices.

Roberta RAFFAETÀ: *The allergy epidemic, or when medicalisation is bottom-up*

Increasingly people claim to be allergic and there is a wide use of the term that exceeds biomedical borders. This paper derives from a research conducted between 2004 and 2008 in Verona

(Italy) and focus on discourses of allergy sufferers, allergologists and alternative medicine practitioners. It contends that allergy has gained an enormous success because it is a powerful metaphor to express the contemporary distress of people in their relationship with the environment.

Vibeke STEFFEN: *Intrusive agents and permeable selves. Spirit consultations in Denmark*

An unknown number of people in modern societies suffer from disturbing problems such as encounters with spirits or ghosts and misfortunes transferred from random passers-by. We might think of these experiences as psychotic symptoms to be treated by medicine. The participants in this study, however, chose to deal with their problems in other ways by consulting spiritualist mediums. The aim of the article is to explore the character of their problems and the ways in which they were dealt with.

Madel LUZ & Rafael S. MATTOS: *Fibromyalgia, bodily practices and work in Rio de Janeiro*

Fibromyalgia is a body pain syndrome. Duration, intensity and extension of zones of pain, functional disability and incapacity for work and daily activities are impressive. Loss of self esteem and social isolation are present in the subjects with the syndrome. A Program for women with fibromyalgia showed that after months developing collective bodily practices, their symptoms regress. However when they are able to come back to work the symptoms come back. Loss of senses in work, and work regime appear as possible causes.

Erica EUGENI: *Living a chronic illness: a condition between care and strategies*

The aim of the article is to explore the condition of patients who receive haemodialysis treatment, looking at how they live their permanent condition of illness allowed by a specific treatment that requires patients to spend a long time in hospitals, depending on the artificial kidney and on the health practitioners that ask the patients to develop self-discipline and body techniques. The research has showed how the patients react to the forced changes in term of sense of identity and life style.

Lina MASANA: *Invisible chronic illnesses inside apparently healthy bodies*

Some chronic illnesses may not be visible to the gaze of others. Mistaking a sick person for a healthy one, the delegitimation of illness experience, and/or the lack of biomedical diagnosis hide the experience of suffering and put sideways some care needs of people affected. The aim of this article is to address the question of the social treatment of the body exploring the explanatory models of these 'healthy-sick' bodies in order to shed light on invisibility paradox through four analytical constructs: physical, social, medical and political invisibility.

Claudie HAXAIRE, Francis COUTURAUD and Christophe LEROYER: *The risk of venous thrombosis and its transmission: medical progress and loss of body image*

A recent clinical study shows that the determination of family risk of idiopathic thrombosis using clinical variables is more reliable than genetic test. But for the patients and their families, these advances in medical knowledge are a source of bewilderment and dismay, because they make the risk more abstract. They tend to associate the illness with more familiar entities that have more meaningful symptoms, linked to imaginary forms of the material

body. For the thrombosis patient the persistence of discomfort in the affected part of the body take on the significance of corporal memory.

Josep M. COMELLES: *The beast in me. The evolution of mad bodies in contemporary Europe*

The paper compares narratives and ethnographic descriptions of persons labelled as “insane” in relation to excess in the consumption of food and spirits, from the end of the 18th century to the 21st century. The comparison reveals that in the studied period the scholastic concept of “excess” - coming from Aquinas - plays a decisive role in the shaping of some eating behaviors related to food and spirits far beyond the idea of statistical normality. The paper centers particularly on the case of excess of food consumption, and the concept of excess reveals the moral implications of this kind of behaviors.

William S. SAX: *From Soft Discipline to Hard Pleasure: “hegemonic body images” in north India*

One “traditional” ideal male body in India is strong, flexible, and soft; the kind of body that results from disciplining one’s exercise, as well as one’s diet and sexuality. The latter is important because semen is regarded as the source of physical and mental strength. But a new ideal male body -- lean, muscular, and hard -- now dominates the public imaginary. Advertising suggests that such a body is to be achieved through consumption rather than discipline, and that it does not serve health, but rather sexual pleasure.

Pierre-Marie DAVID: *Asymptomatic cholesterol, “wonderdrugs” and Western forms of pharmaceutical inclusion*

The use of statins is discussed in the context of asymptomatic cholesterol bodies. Access to statins as cholesterol-lowering drugs is examined as a biopolitical issue from a science studies' perspective. From the invention of cholesterol to the medications used in treating it, we try to trace and document the process linking science, pharmaceuticals and politics. We describe Western forms of pharmaceutical inclusion comparing the use of global “wonderdrugs” in the US, the UK and France.

Catherine RÉMY: *Redefining the boundaries of Humanity. The case of allo- and xenotransplantation*

The objective of the paper is to analyze allotransplantation and xenotransplantation together, and to investigate their impact on the definition of the boundaries of humanity. We focus on two controversies: the first concerns an attempt at xenotransplantation on a dying American baby, while the second concerns the harvesting of several organs on a young French man who died in a bicycle accident. Through the practice of transplantation, an astonishing new scale of being emerges.

Baptiste MOUTAUD: *From the experimental body to the experimental patient. Medical experimentation in neuroscience*

This chapter sets out to explore the forms of medical practice that arise from the application of therapeutic biotechnologies. The purpose is to describe how the use of a neurosurgical technology, Deep Brain Stimulation, for the treatment of neurological and psychiatric disorders in a French hospital creates new configurations of collective practices, by (re)aligning the objectives and practices of a variety of actors, and by developing new entities in the course of its experimental development.

Bernhard HADOLT: *'Siting' Genetic Counselling for Pre-symptomatic Genetic Testing in Austria*

Molecular genetic diagnostics has made diagnosable the predisposition to "late onset diseases" long in advance of any symptoms. Such predictive tests give rise to a number of medical, social and political issues. Genetic counselling that observes certain principles is commonly practiced to protect clients from the unwanted ramifications of his/her genetic information. However, practices of clinical counselling are also shaped by other logics. I argue that the specificities of the various counselling modes found in Austria can be understood best as effects of how counselling practices are 'sited', that is *where* they exist and happen.

Sylvie FORTIN: *Can Bioethics Embrace Diversity?*

The anthropological and sociological critiques of bioethics are numerous, in particular how bioethics lacks an empirically-based approach to the norms and values it is specifically centred on. As an anthropologist, studying the clinic as a plural space where norms and values are daily negotiated (or not), this paper will explore how medical knowledge and physicians' values and practices are intertwined in establishing the "norm frame" within the hospital.

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The question of the social treatment of the body and its transformations emerges in relation to issues of varying types (economic, therapeutic, ideological, cultural, aesthetic, commercial, technical). This book examines the various ways of managing bodily symptoms or transformations and the social stakes and systems of knowledge which relate to them, both on the medical and social level. The contributions provide analyses that concern a broad range of countries. Through the themes it tackles and the subjects it examines, this book reveals both the universal nature of the questions it asks, and the evolution of the objects and approaches of anthropology itself.