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 moment[2].

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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 (Good[3], 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-self[4] 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 illnesses[5], some characteristics specific to some types of illnesses, sufferings or unwellnesses[6] raise a particular problematic.

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[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 diagnosis[7], multiple unexplained symptoms (MUS[8]) 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

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[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 disorders[9], 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

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[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 us[11]. 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 problems[12] 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

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[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 informs[14] 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

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

[14] As 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

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[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*, 22ªedición) 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 consider 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 ill[17]. 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

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[17] The 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 culturally[18] (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

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[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 sensitivity[19] 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

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[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 situation[21]. Although they accept the authenticity of their symptoms, being

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[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 legitimation, 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 neglected[22] (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* (CAM[23]), 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:

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[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 problem[24], 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-world[25], 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).

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[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

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[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 sidelined[28]. 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

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[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 approach[29], 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.

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[29] Following MERLEAU-PONTY's (1993) *embodiment* analysis.

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