

Talking About the Disease

Sharing Experiences of Hepatitis C Online

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This article describes the experience of people who have hepatitis C, particularly their daily life and their experiences regarding the disease expressed in forums on the internet. It means a personal identity, and also a belonging's feeling to a group, the "hépatant" people. The issue of patient's identity was reflected upon, considering a context in which sickness groups start to be formed through associations and forums on the internet, making inter-pares support an essential feature of the patient's identity.

Key-words: disease; hepatitis C; internet forums; identity; "hépatants".

ARQUIVOS DE MEDICINA, 24(4):131-35

INTRODUCTION

In an anthropological approach (1-12), and from an heuristic perspective, I will try to explore the case of hepatitis C, whose features make it a singular case: it is chronic but curable, it presents few if none symptoms, but its treatment frequently provokes many side-effects, so that the attempt at a cure renders it symptomatic, creating a paradoxical situation, between the start of the therapeutic process and the frailty caused by its treatment.

The current treatment for hepatitis C, which includes parenteral and oral drug administration, presents a success rate around 50%. However, its side-effects are numberless: depression, fever, muscle pains, headaches, fatigue, nausea, weight loss, hair loss, psychological disorders, thyroid dysfunctions, etc. - causing 15% of patients who start the cure to abandon treatment (13). According to a study carried out in 2002 (14), 75% of the patients state that hepatitis disturbs their daily life, mainly because of a frequent chronic fatigue, a regular medical assistance, and the side-effects for people undergoing treatment, whose can be particularly significant, preventing them from working.

The goal of the present research was to find out to what extent the disease, its treatment and cure influenced not only patients' everyday life, but also their identity, how they represent themselves as well as the others, the non-sick. The issue of patient's identity was reflected upon, considering a context in which sickness groups start to be formed through associations and forums on the internet, making groups support an essential feature of the patient's identity.

Considering a context in which "people with hepatitis

C rarely get to speak for themselves about their experiences of living with a chronic, potentially terminal and highly stigmatized disease" (41: 273), internet forums gain an ever growing importance as places for getting information, exchanging experiences, and expressing feelings about the disease. The issue of patient's identity is the center of the analysis of the patients' narratives, considering a context in which sickness groups start to be formed through associations and forums on the internet, making inter-pares support an essential feature of the patient's identity.

The analysis is based on written testimonies collected in virtual forums on the internet, attending to the new socializing spaces provided by this medium and the increasing relevance of such spaces for the management and experience of disease, as well as the relevance of this means of communication, due to its ability to allow communication with others without leaving the house, which is essential for certain patients in treatment, whose bodies have become weak from medication but whose need for support and understanding is crucial at that particular juncture.

METHODS

I started by collecting testimonies from two forums¹, in 2004, and did a content analysis. The year after, I

¹<http://fr.groups.yahoo.com/group/hep-cie> and www.hepatites.net. The first one is a little discussion group. The last one is the most visited hepatitis forum on the internet, in France, where there are four forums. That choice was motivated by the necessity of perceiving possible differences between a young and a big forum. No particular difference was detected.

contacted members of these forums to conduct in-depth interviews in order to gain a better understanding of their histories as patients. I interviewed five women and five men, with ages ranging between 30 and 65, and living in the Paris metropolitan area. That choice was motivated by the necessity of perceiving both female and male discourses, in one hand, and to include individuals of different age groups, in the other hand. The depth of the analysis and the ethnographical character of this research justify the apparently small number of interviews, which is considered sufficient for the aims of this study. Interviews were tape recorded with peoples' consent, but their names were changed to safeguard confidentiality. This choice assured a varied sample in terms of gender and age, even if the statistical representativeness is not an issue on this. The statements presented are translated from French. For the analysis, I used content analysis, helped by the theoretical narrative, a theory² that uses narrative to describe people experience of chronic illness (16-21, 25-30, 37-40).

Forums on the internet³ are a meeting point for patients, whether they are personally acquainted or not, where they share their experiences of the illness and build networks of mutual help. The language of disease is inscribed in the body, which anthropology seeks to understand through an approach that considers meanings and logic of behavior (3). By means of the personal histories, I try to describe the emergence and management of disease within the scope of individual existences, in the heart of which the individual person tries to confer coherence to events. The manifestation of the disease brings about the need to name, understand the origin, express, and give sense, through a "semantic network" (28), to a number of notions and symbols that structure the experience of the disease, as well as the need to reestablish the personal identity (22,23,29,30).

RESULTS

From initiates to (h)épatants: reconfiguration of painful experiences

This investigation was carried out in France, and I should point out that there is a French word to describe carriers of chronic hepatitis, a neologism which is a pun on the word *épatant*, without an *h*, meaning amazing. The fact that there is a specific term to name a group of people sharing a common feature is a first indicator of these patients' group awareness.

In France, there are some associations dealing with hepatitis. Their goal is to provide information and give support to people infected with hepatitis. The term *hépatant* to describe members of these associations was initially

coined by a member of the association SOS Hépatites, and later extended to everyone living with any kind of hepatitis.

Initiating the therapeutic process usually triggers or strengthens this search for forums and the need to share information, experiences and feelings with other people suffering the disease. In fact, *hépatants* refer to members who have gone through their first, frequently painful, experience of treatment, as *initiates*. Some of the discourse denotes the high esteem in which patients who have already undergone several treatments are held. A painful experience is thus turned into an instrument of recognition. Those who are cured are also praised and congratulated as if the patient were the only one responsible for that *feat*. The diseased person is admired.

The sick person initially rejects this new status derived from the presence of a chronic disease which changes the image s/he has of him/herself, like a brand stuck on the body (33).

Sometimes the sick person won't start a process of medical care immediately, refusing to play the role of patient, especially in being followed by a doctor and starting medication, fearing that the disease might invade his/her whole existence and personal identity (34). Being dismissive of the disease is another typical reaction when confronting the diagnosis and this helps the patient to manage both the disease in its organic and bodily aspects, as this new biographical and identity element: the status of the chronically sick. The sick person may also invert the value scale associated with chronic disease and perceive it as "something good", seeing it as something other than misfortune (35).

To be an active *hépatant* – look for medical information, share experiences and narratives about a common disease, learn strategies to improve the quality of life, help each other – is a way to a way to revaluing patient's status and giving a new meaning to the disease.

From hépatants to cured persons: challenges and transformation

Being diagnosed with a disease introduces a biographical break. Then, the cure implies a *difficult stage* and a *renewal* or a *transformation*, both for those going through a period of mourning the disease, parting from everything that reminds them of it, as for those who remain one way or the other attached to the disease. The latter are those who, as active members of an association, give continuity to the *world of hepatitis* and call themselves *cured* or even *cured sick persons*, in an allusion to their past experience of the disease. There is a need to retain the experience of the disease. They continue, for example, to contact the sick through forums on the internet, and to further their knowledge of the disease, namely within the sphere of the associations' activities.

The cure is seen as a difficult stage because for years, life was led in a particular way, making regular visits to the doctor, abstaining from alcohol, etc.; having an acute awareness of the presence of a virus. And after the cure:

²Narrative theory is based on the concept that people are essentially storytellers and defends that individuals approach their social world in a narrative mode and make decisions and act within a narrative framework.

³I checked off four french forums on the web.

“everything disappears. (...) suddenly your host leaves you!” (Catherine, 45 years old, a stopped treatment because of thyroid disturbs).

This change, both in everyday life and self consciousness, brings about an identity disruption which the individual will try to solve.

Therefore, the patient who undergoes a treatment that succeeds at seroconversion goes through two stages of change that have consequences on his/her identity: first s/he feels the presence of the disease with treatment and the subsequent side-effects it entails, and then, with the cure that comes after treatment, s/he ceases to be sick⁴.

Thus, one of our informants, whose treatment introduced the first major change in everyday life, initiating a process of medical care, and a shift in his perception of himself, started psychotherapy – not during treatment as the doctor had suggested – but later, when he finally became cured and underwent a new set of changes, such as a change of residence and diet. The cure signaled a second transformation: a transformation in lifestyle:

“There is an idea of renovation. (...) I returned to my parents’ house where I grew up; to my childhood room - maybe it is symbolic... Besides that, I started psychotherapy (...) It’s the beginning of a second life...” (François, 41 years old, last treatment finished a year back).

Motives to look for forums online: information and feeling of belonging

The awareness of being sick frequently arises with the first treatment, since the disease goes unnoticed for several years, displaying no obvious symptoms. Treatment implies starting medication, and their side-effects, that cause physical and psychological discomfort makes the disease tangible, carrying with it the notion of sickness, or even of being a sick person.

“[The first treatment] it was still with interferon, three times a week, but I took induction doses, I took ten million unit doses for fifteen days, which finally made me so weak that I really felt sick and accepted being labeled as sick.” (Mireille, 45 years old, undergoing treatment).

The need to contact other “hépatants” also derives from a feeling of being misunderstood. Others cannot understand what it means to have hepatitis C, and especially to undergo treatment.

“People who don’t have a hepatitis, you can’t talk to them about it, I mean, it’s just as with any other disease, you quickly realize that others can’t share what you are going through. How can they, it’s impossible. You need to have lived through it yourself.” (Aline, 50 years old, last treatment finished a few months back).

Hépatants frequently use medical terms in the forums which a newcomer would hardly understand. The abbreviations, as well as certain specific expressions add an obstacle to initiates’ understanding, emphasizing the

distinction between members, *hépatants*, and others. The following terms, acronyms, abbreviations, and expressions are a few examples: *transa* = transaminase; *ES* = side-effects; *ttt* = treatment; *INF* = interferon; *riba* = ribavirin; *QVD* = quality of life; *MG* = general practitioner.

These individuals are driven to forums on the internet mainly in search of information, but also out of a need to express their experiences of the disease, a need for comforting and for sharing with people facing the same predicament.

The treatment, which is arduous and long (24 or 48 weeks, depending of viral genotype) is the moment when bonds with other forum members become stronger. The sick person, frequently too exhausted to leave the house, finds in the forums a link to the outside world, and not the world at large but the world of *hépatants*, “the only ones who understand” (Catherine, 45 years old, a stopped treatment because of thyroid disturbs), as says Aline (50 years old, last treatment finished a few months back):

“During treatment there are moments when you go crazy (...). At that moment, all the people you have ever talked with [on forums] are there to tell you: ‘you must hold on, it will be over soon’. (...) This allows one not to feel completely detached from the world. Because that is the problem, you feel completely disconnected from the world. And these [forums] sustain a relationship”.

There is a feeling of belonging to a group which shares a common experience, and a belief that others “cannot understand” this experience, as well as the desire to communicate with members of that group. This communication occurs on the internet, but also includes meetings that are arranged on the forums as well as self help groups organized by the associations.

Reaching out to people who share a common experience also helps fight isolation and self stigmatization, allowing patients to come to terms with their disease (15).

CONCLUSION

In social representations, the disease is associated to the pathological sphere (2), to incapacitation, and to the risk of death (32), causing the patient to lose self esteem and even become anxious about death (24). The announcement of the chronic disease is experienced as a biographical break.

The hepatitis C treatment stage is a second biographical break and it is too experienced as an ambiguous moment, because it unbalances individuals, their everyday life, the image they make of themselves, their relations with others, their perception of others, but at the same time it brings the hope for a cure, for a better quality of life and for a longer life expectancy. It is also a moment in which the person is “immersed in the disease”, it is a “parenthesis in life”. Thus, coming out of this parenthesis people need to reestablish their identity as healthy individuals, and sometimes as social beings that work, have social relations, sexual lives, etc. They must assimilate new identity features that give coherence to their self

⁴I am considering only those patients that benefit from a long term seroconversion after treatment

representations, including the experience of the disease. It is a process of identity reconstruction which is accompanied by a process of physical recovery.

A cured person may even feel some emptiness. Losing the sick status means losing the social ties attached to the state of sickness, such as doctors, psychologists and members of help groups, and thus their identity as a sick person.

“That is actually kind of strange; believe me, because during my treatment, I was sick, but at the same time, I had a lot of support, psychologically, I had the psychiatrist who saw me, then there was my doctor, who followed me closely; even my family doctor, he listened to me. Besides that, there was the hepatitis.net site which has really helpful. Therefore, when I finished treatment, everything stops suddenly. Treatment stops, so supposedly you stop needing help... You are completely stripped bare of your life (...) So when all of a sudden you're supposed to feel good because it's all over, but you are left with nothing to fill up your life... That came as a shock, it was weird...” (Aline, 50 years old, last treatment finished a few months back).

The cure may also generate a feeling of losing secondary advantages (what is considered advantageous in the sick status) to the patient used to being cared for, and being the object of special attention from those around him/her; of being socially and emotionally comforted in a very particular way; having extra social benefits, etc. (31).

The cure thus represents still another biographical break, after the one that comes with the announcement of the disease and the one that occurs when treatment commences. It is a difficult moment, and one which may also cause feelings of guilt; the guilt for having *succeeded* in the cure while others *fails*.

Even considering that there are variations in the individual experiences of the disease, treatment and cure, there is certainly a “before and an after hepatitis”, in the words of one of the informants.

People with hepatitis C rarely get to speak for themselves about their experiences of living with a chronic, potentially terminal and stigmatized disease (41). The forums on the internet are a space for that, and are described by my informants as an important part of the treatment which permitted them the cure.

REFERENCES

- 1- Laplantine F. L'anthropologie de la maladie. Paris: Payot. 1986.
- 2 - Canguilhem G. (1966). Le normal et le pathologique. Paris: Presses Universitaires de France. 1966.
- 3 - Augé M, Herzlich C. Le sens du mal. Anthropologie, histoire, sociologie de la maladie. Paris : Editions des archives contemporaines. 1984.
- 4 - Friedson E. La profession médicale. Paris: Payot. 1984.
- 5 - Fainzang S. La Relation médecins-malades: information et mensonge. Paris: Presses Universitaires de France. 2007.
- 6 - Zola I. Culture and Symptoms. An Analysis of Patients' Presenting Complaints. *American Sociological Review* 1966;31:615-30.
- 7 - Kleinman A. The illness narrative. Suffering, healing and the human condition. New York: Basic Books. 1988.
- 8 - Carricaburu D, Ménoret M. Sociologie de la santé. Institutions, professions et maladies. Paris : Armand Colin. 2004.
- 9 - Fassin D, Memmi, D. Le gouvernement des corps. Paris: Éditions d l'École des hautes études en sciences sociales. 2004.
- 10 - Bonnet D. Au-delà du gène et de la culture. *Hommes et migrations*. 2000;1225:23-38.
- 11 - Dufresne J, Dumont F, Martin Y. Orgs. *Traité d'anthropologie médicale*. L'Institution de la santé et de la maladie. Les Presses de l'Université du Québec / Presses universitaires de Lyon. 1985.
- 12 - Trostle J. *Epidemiology and culture*. New York: Cambridge University Press. 2005.
- 13- Pawlotsky JM, Dhumeaux D. Hépatite C. Paris: Éditions Médicales et Scientifiques. 2004.
- 14 - SOS Hépatites. *Vivre avec une hépatite virale*. *Bulletin SOS Hépatites* 2003;22:3-6.
- 15 - Fainzang S. L'anthropologie médicale dans les sociétés occidentales. *Récents développements et nouvelles problématiques*. *Sciences Sociales et Santé* 2001;19:5-27.
- 16 - Bruner JD. Life as narrative. *Social Research* 1987;54:11-32.
- 17 - Good B, Good MJD. Au mode subjonctif. La construction narrative des crises d'épilepsie en Turquie. *Anthropologie et Sociétés* 1993;17:21-42.
- 18 - Hydén L. Illness and narrative. *Sociology of Health and Illness* 1997;19:48-69.
- 19 - Ricoeur P. *Temps et récit*, vol. 3: Le temps raconté. Paris: Seuil. 1985.
- 20 - Draperi C. Dire la maladie : regard philosophique et anthropologique. *Revue Ethique et santé* 2004;1.22-44.
- 21 - Zborowski M. Cultural Components in Responses to Pain. *Journals of Social Issues* 1952;8:6-30.
- 22 - Bury M. Chronic Illness as biographical disruption. *Sociology of Health and Illness* 1982;4:67-82.
- 23 - Charmaz K. Loss of self: a fundamental form of suffering in the chronically illness. *Sociology of Health and Illness* 1983;5:168-95.
- 24 - Herzlich C, Pierret J. *Malade d'hier, malades d'aujourd'hui*. De la mort collective au devoir de guérison. Paris: Payot. 1984.
- 25 - Ménoret M. *Les temps du cancer*. Paris: CNRS Éditions. 1999.
- 26 - Duarte LFD, Leal OF, Orgs. *Doença, sofrimento, perturbação: perspectivas etnográficas*. Rio de Janeiro: Editora Fiocruz. 1998.
- 27 - Guibentif, P. Tentativa para uma abordagem sociológica do corpo. *Sociologia, problemas e prática* 1991;9:77-87.
- 28 - Good B. Comment faire de l'anthropologie médicale ? *Médecine, rationalité et vécu*. Le Plessis-Robinson: Institut Synthélabo. 1998.
- 29 - Malewska-Peyre H. L'identité comme stratégie. In: Costa-Lascoux J, Hily MA, Vermes G. (eds). *Pluralité des cultures et dynamiques identitaires*. Hommage à Carmel Camilleri. Paris: L'Harmattan. 2000.
- 30 - Berting J. Identités collectives et images de l'Autre. *Hermès* 2001;30:41-58.
- 31 - Shützenberger AA. *Vouloir guérir*. Paris: Desclée de Brouwer. 2009.

- 32 - Kleinman A. Santé et stigmaté. Note sur le danger, l'expérience morale et les sciences sociales de la santé. *Actes de la recherche en sciences sociales* 2002;143:97-9.
- 33 - Adam P, Herzlich C. Sociologie de la maladie et de la médecine. [1^a ed.: 1994] Paris: Nathan. 2002.
- 34 - Evans RG, Barer ML, Marmor TR, Orgs. Être ou ne pas être en bonne santé. Biologie et déterminants sociaux de la maladie. Les Presses de l'Université de Montréal / John Libbey Eurotext. 1996.
- 35 - Taïeb O, Heidenreich F, Baubet T, Moro MR. Donner un sens à la maladie: de l'anthropologie médicale à l'épidémiologie culturelle. *Médecine et maladies infectieuses* 2005;35:173-85.
- 36 - Tap P, Org. Identité individuelle et personnalisation. Production et affirmation de l'identité. Colloque International Toulouse, septembre 1979. Toulouse: Privat. 1980.
- 37 - Laplantine F. Corps malades et salut par l'écriture dans la littérature autobiographique contemporaine. *Lumière et vie* 1984;166:29-43.
- 38 - Laplantine F. Je, nous et les autres. Paris: Le Pommier. 1999.
- 39 - Quinche F. Récits sur la maladie. Maladie et récits de vie. D'un paradigme narratif à un paradigme dialogique. *Revue Ethique et santé* 2005;2:82-7.
- 40 - Ricœur P. Soi-même comme un autre. Paris: Seuil. 1990.
- 41 - Körner H. Negotiating treatment for hepatitis C : Interpersonal alignment in the clinical encounter. *Health* 2010;14:272-91.

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