

Hernán Cuevas Valenzuela/Michaela Th. Mayrhofer

The sick as biological citizens? How patient-user organizations reconfigure the field of health and illness

Keywords: biological citizenship, patient-user organizations, biopolitics, HIV/AIDS, myopathies

Based on a qualitative two-case study of patient-user organizations, this article examines how politicised and radical patient-user organizations can effectively challenge biopolitical governmentality, its medical institutions, as well as its configuration of power/knowledge and forms of subjectivation by using what we consider to be affirmative biopolitical strategies. These strategies, the authors argue, empower the patient as biological citizen because patient-user organizations challenge dominant contemporary views on health and illness by making specific citizenship claims and rearticulate the patient as active agents.

Der Kranke als biologischer Bürger? Wie Patientenorganisationen die Kategorisierung zwischen Gesundheit und Krankheit neu formen

Schlüsselwörter: biologische Bürgerschaft, Patientenorganisationen, Biopolitik, HIV/AIDS, Myopathie

Basierend auf zwei qualitativen Fallstudien von Patientenorganisationen zeigt dieser Artikel auf, wie politisierte und radikale Patientenvertretungen biopolitische Gouvernementalität, traditionelle Institutionen des Gesundheitswesens als auch deren Macht- und Wissensstrukturen sowie Ausformungen von Subjektivierung durch affirmative biopolitische Strategien infrage stellen. Diese Strategien, so die AutorInnen des Beitrags, bemächtigen die PatientInnen als biologische/r BürgerInnen aufzutreten, und mittels der Patientenvertretung die vorherrschende Meinung zu Gesundheit und Krankheit durch die Formulierung spezifischer Bürger(rechts)ansprüche neu zu definieren. Dies wiederum erlaubt die Etablierung des/der PatientInnen als aktive AkteurInnen.

Hernán Cuevas Valenzuela

Escuela de Ciencia Política (School of Political Science)

Facultad de Historia y Ciencias Sociales (Faculty of History and Social Sciences), Universidad Diego Portales
Avenida Ejército Libertador 333, Santiago de Chile

E-Mail: hernan.cuevas@udp.cl; hcuevasster@gmail.com

Michaela Th. Mayrhofer

Institute of Pathology, Medical University of Graz

Auenbruggerplatz 25, 8036 Graz, Austria

E-Mail: michaela.mayrhofer@medunigraz.at

1. Introduction

In this article, we explore how radical patient-user organizations employ what we consider affirmative biopolitical strategies to contribute to the changing relationship between nature and culture (“biosociality”, Rabinow 1996; Rabinow 1999)¹ by using the concept of “biological citizenship” (Rose 2006; Rose/Novas 2005). In order to substantiate our claim, we systematically compare in a two-case study approach (Yin 1994) two politically influential patient-user organizations: the AFM (the Association Française contre les Myopathies, a French patient advocacy organization that struggles against neuromuscular disease), and Vivopositivo (a Chilean umbrella organization that brings people who live with HIV/AIDS together). The two-case study strategy allowed us to develop some theoretical insights through the rationale of comparison that would not have been possible through a single case study. It also allowed us to avoid merely accidental impressions, and advance some general insights. The selection of the cases was purpose driven: we wanted to study politically engaged patient-user organizations with a discourse on citizenship. Our qualitative descriptions are made on the basis of research done on news articles, documents, websites, ethnographic observation, and a small number of semi-structured interviews with leaders and key actors from each organisation.² Through our research we concluded that AFM and Vivopositivo empower the “patient” as a biological citizen because both of these patient-user organizations challenge dominant contemporary views on health and illness by making specific citizenship claims. Our main conclusion is that politicised and radical patient-user organizations, such as Vivopositivo and the AFM, can effectively challenge biopolitical governmentality, its medical institutions, as well as its configuration of power/knowledge and forms of subjectivation by using what we consider to be affirmative biopolitical strategies.³ Before going into our empirical analysis, we shall briefly present the concept of biological citizenship and its relation to biopolitics.

2. Biological Citizenship and Biopolitics

The concept of biological citizenship⁴ seems evocative to us because it has the potential to examine already known practices of patient-user organizations under a new light. By adopting this concept, we may emphasise the practices of freedom and self-government (Tully 2002) embraced by patient-user organizations. Such socio-cultural practices, frequently framed in a discourse of citizenship, involve their refusal to accept their identity as sick people or their experience as destiny. This leads us to claim that biological citizenship needs to be conceived as both a new political identity and a new phase in the evolution of citizenship, thus going beyond the traditional concept of citizenship as a status of recognition and membership of the political community conferred by the state. Biological citizenship results of an expansion brought about by the formulation of new rights that empower people in the field of health and illness.⁵ Biological citizenship is an emerging political identity that, from the foundation of a discourse of citizenship, re-articulates citizens’ relationships to their own biological bodies through socio-cultural practices. These practices politicise group-based concerns about biomedical issues and contribute to the contentious political issues that have arisen in the field of health and illness in recent decades. Consequently, we claim that biological citizenship constitutes an emergent form of alternative subjectivation which opposes the dominant forms of subjectivation in the field. By subjectivation, we mean the process of constituting a subject by using an array of dispositives,

including discourses, disciplinary mechanisms and techniques, and technologies of the self (Foucault 2000). The constitution of subjectivity is context dependent and establishes concrete regimes of the self. A sick person conceived as “the patient” is traditionally attributed as passive, a receiver of applied knowledge, a mere object of medical intervention and, of course, a carrier of a disease or a harmful condition. When subjectivised as a biological citizen, in contrast, the so-called “patient” or “sick person” has to be de-subjectivised as such, hence allowing his/her constitution as an active agent of self-promotion, (co-)creator or articulator of forms of knowledge, who advocates for his or her own health status. In some of our interviewees’ accounts we came across this double-process of de-subjectivation of the dominant discourse of the “patient” and alternative subjectivation as a biological citizen. Indeed, interviewees not only advocate for their rights (subjectivation as biological citizen), but also frequently rejected the hegemonic image of their health status as sick (de-subjectivation as sick person). Moreover, we have found that the interviewee, especially when supported by a politicised patient-user organization of which he/she is a member, can rearticulate his/her diagnosed health status with his/her own lay beliefs and forms of activist knowledge. These accounts are possible because there is an emerging configuration of power/knowledge that rearticulates the relations between the citizen, his/her experience of the body, health, illness and the biomedical establishment and its discourse. In its turn, the practice of knowledge production in patient-user organizations involves the active participation of their members and includes their views and interests qua biological citizens. In our opinion, this alternative production of power/knowledge along with its corresponding form of subjectivity constitute an other-to-power that can best be described as affirmative biopolitics and a biopolitics from below (Hardt/Negri 2000; Lemke 2011). We claim that affirmative biopolitics is both a form of resistance to the power of the biomedical establishment⁶ and a search for freedom.

Although Foucault always maintained that the individual is “an effect of power” (Foucault 1970, 98; Foucault 1977; Foucault 2000), he also recognized counter-powers and agency (Foucault 1977, 63, 219, 273; Foucault 2000, 154, 294–295, 324). Consequently, he also studied “the way a human being turns him – or herself – into a subject” (Foucault 2000, 326); especially through the ethical practices of “self-care”, “liberation” and “practices of freedom” (Foucault 1977, 93–106, 281–302). We explore this ambivalence in Foucault’s notion of power and its relation to the subject for our purpose of best explaining the constitution of the biological citizen and the emergence of affirmative biopolitics from below. We thus distinguish between biopolitical strategies of control and affirmative biopolitical strategies and their correlative forms of subjectivation. The former include the production of biomedical knowledge, genetic testing, classification and separation of groups, collective hygiene techniques, health care policies, and management of reproductive rights and population control, all of which contribute to the constitution of the sick person as a patient under the hierarchy of the medical expert. In contrast, affirmative biopolitical strategies include the organization of counter-powers through patient-user organizations, the production of unconventional forms of power/knowledge and alternative modes of subjectivation. Although this conceptual distinction may initially seem rather simplistic, it serves us to differentiate analytically two basic and distinctive logics. As will be seen in our empirical analyses, they are frequently combined in the formation and action of patient-user organizations. In the coming sections, we will first present some general aspects of Vivopositivo and the AFM to then show how they oppose biopolitical strategies of control, exercise a distinctive form of power – an affirmative form of biopolitics – and foster alternative modes of subjectivation.

3. The AFM and Vivopositivo

The AFM came about in 1958, when Yolaine de Kepper, a mother of four children affected by Duchenne muscular dystrophy, began the Association Française pour la Myopathie as a platform for patients of rare diseases and their families. Today, after some restructuring and fundraising by the Téléthon⁷, this patient-user organization has become a financially independent and politically powerful private non-profit patient advocacy group that combines its activists' energy with a high level of professionalism and its own biomedical research activities (Rabinow 1999; Rabeharisoa/Callon 1999). It is this financial independence, which the AFM has gained thanks to Téléthon that makes it so powerful. In 2011, for instance, Téléthon had raised 94 million euros. On its website it states that with this money "research programs will keep going on and the first clinical trials will produce results" (<http://www.afm-telethon.com/the-telethon.html>, last accessed: 24.5. 2013). Indeed, most of the money raised by Téléthon is used for research activities and in line with the AFM's fundamental goals, which are (1) "to help patients and their families in all areas of daily life" and (2) "to support research on neuromuscular diseases with a view to eventually finding a cure for them" (Rabeharisoa 2003, 2130), while employing a do-it-yourself approach insofar as they do not rely on the state but on their own (organizational) strength. Since its foundation, the AFM has followed the principle of turning "towards science" but has refused "to be controlled by scientists", which was depicted as the "partnership model" between scientists and patients. This model emphasises the equal status of patients as partners of experts and scientists in knowledge generation and identifies patients as decision makers of their own research policy who do not delegate "decision-making powers on the definition, management and evaluation" of their research policy to scientists (Rabeharisoa 2003, 2132).

When the Chilean state made the unilateral decision to cut off free provision of bi-therapy in 1997, it created a political opportunity for resistance to be organized among people living with HIV/AIDS, leading to the creation of the National Association of Organizations of People living with HIV/AIDS (COORNAVIH), which one year later changed its name to Vivopositivo. Vivopositivo states that its mission is to "offer a well-rounded solution to the threats and challenges posed by the epidemic in order to improve the quality of life of people living with and affected by HIV/AIDS"⁸ in a participative and representative way. Likewise, Vivopositivo aims to improve the quality of life and the social and affective milieu of its members. To do so, it pursues the following objectives: the defence of human rights, citizenship rights, sexual and reproductive rights, universal access to treatment, health promotion, prevention and the strengthening of the network of national organizations of people living with HIV/AIDS and their relatives. Today, Vivopositivo is an umbrella organization that brings together close to 40 groups across the country. It has a key role as spokes-organization vis-à-vis the state and its policies. It co-participates in important decision making processes, such as acquiring drugs and doses at the national level and designing national public prevention campaigns. Although Vivopositivo has collaborated with the Chilean state in matters such as those mentioned, it has also sued it for cases of human rights violations, among the most notorious of which was regarding the limitation of the reproductive rights of women living with HIV/AIDS.

The AFM and Vivopositivo evolved from informal networks that, within the wider phenomenon of health social movements of the last decades (Brown et al. 2004; Brown/Zavestoski 2004), grew into more institutionalised and bureaucratic patient-user organizations that cared not only for the sick or disabled, but also for their kin and partisans. They challenged not only established (medical) authorities, health policy realms and medical belief systems, but also research prac-

tices that objectivised people as the sick. The AFM sponsored Généthon DNA and Cell Bank provides a nice example for this claim. The DNA and cell bank is part of the research company Généthon, to which patients donate their blood, typically through the intermediary of a physician. Frequently, however, the patients articulate their donations as acts of self-empowerment, speaking of “their blood” deposited in “their bank”. In other words, the donors do not see themselves primarily as “sick persons” but as active agents and co-producers of scientific knowledge by not only permitting through their informed consent but through their partisan work as members or supporters of the patient-user organization.

The AFM and Vivopositivo not only fight against disease; they also struggle against forms of exclusion, stigma and discrimination. Through the collective practices and discursive strategies of patient-user organizations, negative personal experiences and stereotypes of illness and disability are perceived as sources of collective grievance and transformed into socio-political demands against the political system in the case of Vivopositivo, and the healthcare system in the case of the AFM.⁹ As a result of this process patient-user organizations become politicised collective illness identities (Brown et. al 2004). They result from an imaginary, cognitive, moral, and emotional bond between individuals who feel that they are members of a broader community. Through our research we found that the shared experience of the body of patient-user organization members’ – which is not limited to illness and disability – and the shared hope for a cure – or at least the hope for a better quality of life – work as effective identity markers.

In our analysis we found that the AFM and Vivopositivo have not only struggled to expand or maintain patient rights, but have also created new rights through their claims based on the health conditions of their members, thus widening the sphere of citizenship. Interestingly, their struggles against forms of the biopolitics of control have frequently been framed in the discourse of rights, both to challenge and to re-articulate illness identity discourses. Furthermore, as we will see in more detail, patient-user organizations have been willing to use forms of expert knowledge – frequently biomedical knowledge – in their favour, a matter to which we turn now.

4. Medicine and Configurations of Power/Knowledge

Deborah Lupton (Lupton 1994; Lupton 2003) has stated that illness is not only a physical, but also a spoken experience of the ill person. Hence, its meaning is socially constructed by different discourses and practices that take place around conceptions of sickness and constitute regimes of truth about health and illness.

The patient’s trust in the physician’s expert judgement has been the quintessential feature of the biomedical regime and the patient-doctor relationship. Such trust is backed up by scientific knowledge and the certification of the doctor as a professional who is able to define “the clinical situation” and intervene in it whereas the “docile patient” has to follow the doctors’ directions (Turner 1995, 194).

However, patient-user organizations such as Vivopositivo and the AFM rebel against this order by challenging the doctor’s unique role of expertise and promoting an active role for the patient, as we discuss now. Whereas patient-user organizations’ discourses attempt to convey the pain and the wider human experience of patient-users’ health and defend the validity of patient-users’ lay knowledge and their pragmatic use of expert knowledge, the aim of the biomedical discourse is to define health and illness in objective terms, to produce cures, determine and manage the population at risk, and to define the relationship between the doctor and the patient. In the coming sections we analyse these central themes in greater detail.

4.1 *Emerging Ambivalencies in Healthcare and Doctor-Patient Hierarchy*

Our interviews with members of Vivopositivo and experts from the Chilean healthcare system show that pastoral power and various technologies of disciplinary control are relevant in the reproduction of experts' power and the biomedical regime. In general, pastoral power is concerned with the regulation, management, and welfare of populations through the exercise of direct or indirect influence by some authority, usually the state (Foucault 2007). Pastoral power is understood as a "caring" force that is working at the same time over the population and over the individual subject (Smart 2004, 98). In other words, pastoral power is both an individualizing and a generalizing power. Here, we interpret pastoral power as a characteristic element of the welfare state, especially in relation to healthcare policies.

Thus, disciplinary technologies, such as free provision of condoms, medical information, medicine, anti-retroviral drugs and emotional contention and counselling, seem equally important as forms of pastoral power. Indeed, these are also represented as services that are provided for free, but always on the condition that the patient undergoes regular check-ups. Regular check-ups are therefore instances where patients have to provide accounts and evidence of their behaviour (a sort of confession), which also allows an updated dataset on patients to be kept (a form of actuarial power).

The hierarchy of power sometimes expresses itself in dramatic personal experiences. We have come across accounts about complaints of patients living with HIV/AIDS against the derogative value judgements of some physicians and health workers. According to these accounts, some women living with HIV/AIDS have been told that they ought not to get pregnant, or should not have sex "since they are HIV positive".¹⁰ Their reproductive rights are limited by the power of the practitioner. There is the case of a woman who was sterilised without her informed consent. And although a quantitative study run by Vivopositivo shows that both medical and administrative health care personnel are not discriminatory, a significant percentage of respondents living with HIV/AIDS were convinced that at least in some occasions they need to wait longer than other patients of the healthcare system and are treated in a bureaucratic manner (Zambra et. al 2004).

The ambivalence of the strategies of patient-user organizations can also be seen in their relation to power, policies and the state. For instance, while Vivopositivo simultaneously criticises discrimination, abuses and oppressions and defends the rights of people living with HIV/AIDS, at the same time strongly fosters the use of tri-therapy, which forces it to maintain a strong tie with the Chilean healthcare system.

The case of the AFM is different because its partnership model fosters a relationship of equality with medical teams and researchers. This is evident, for instance, in the way it supports the establishment and maintenance of DNA and cell banks which collect, store and provide biological material for researchers for the sake of advancing (genetic) research. Accordingly, the AFM as well as Généthon, its non-profit biotherapy R&D organization, decides to foster or decline a particular research project by using scientific review processes that incorporate both experts' and patients' views. Thus, in contrast with some health advocacy movements that seek to confront or resist medical knowledge radically, the AFM not only embraces but also produces this knowledge under its own control.

It seems to us that the particularities of the conditions that affect people from our case studies are relevant in this matter. Patient-user organizations are willing to use scientific evidence to promote their own interests that are largely based on their biological or biomedical conditions.

By doing so, they either develop an ambivalent attitude towards medical expertise and authority in the case of Vivopositivo, or make efforts to incorporate their own expertise on medical knowledge in the case of the AFM. Putting these nuances aside, both organizations, while dependent on scientific knowledge, have the power to simultaneously challenge its dominance.

These ambivalences towards the hegemonic (bio)medical discourse lead us to reconsider the formation of the doctor-patient relationship and the figure of the so-called “patient” in a less deterministic way. Additionally, under neoliberal healthcare policies, the doctor-patient hierarchy is often combined with the idea of “patient” self-responsibility for his/her health (Speed 2011). Today health is frequently articulated as the individual’s moral obligation to remain healthy, avoid risks (Crawford 1985) and to manage his or her own fate (Strauss et al. 1984), which we discuss below.

4.2 *Technologies of the Self, Ambivalences of the Self-Responsible Patient and Practices of Self-Government*

Foucault (Foucault 1998, 16–49) used the term technologies of the self to refer to the various ways in which individuals relate to themselves (sometimes with the help of others) through certain transformative operations to attain some results of control. They should not be seen as purely individualized technologies, because they can be functional to the government of population health. The imposition of medical protocols and the standardization of treatment, medication, physiotherapy, psychotherapy and diets, while disciplining each individual, at the same time facilitate the government of the wider population of similar individuals. These forms of medical, psychological and practical knowledge – a complex configuration of power/knowledge – subjectify the sick person and express a particular ethics in the idiom of pastoral power.

Another element of this ethics is how self-care is functional to the collective (Foucault 2000). When the so-called “sick person” cares for him/herself, he/she also does it for the sake of the community as a whole. This is evident in the case of safe-sex practice of people living with HIV/AIDS. What is important to note here is that these forms of medical, biological and non-scientific knowledge are translated into behavioural guidelines. Through this process, they produce a moralistic effect on the subject. This underlying individualistic ethics of self-care and responsabilisation is functional to a neoliberal governmentality that dissolves public problems. Yet, on the positive side, this moral obligation towards one’s own health opens the possibility for reflexivity and patient-user organization’s intervention, fostering their members’ capacities for self-transformation and self-governance, thus opening the possibility of experiencing disease as something that can be, if not overcome, at least re-defined in terms that make sense to the person living with the condition rather than remaining an objectified medical fact and/or a matter of fate (Clarke et al. 2003, 172). This points to the complex question of the relation between technologies of the self that are supportive of the control of the population, and the possibility of developing some sort of technologies of self-government as practices of freedom (Tully 2002).

In the case of people living with myopathies we can stress the high relevance of genetic issues, such as pre-implantation genetic diagnosis or genetic testing. These practices do not contest the medical gaze *per se*. However, when directed by the interest of the patient-user organization, the meaning they acquire complements and re-articulates the scientific view. The AFM’s activities have, for instance, heavily influenced the drafting of the European Commission

Communication and Council Recommendation on European Action in the Field of Rare Diseases, where the AFM takes a positive stance for genetic testing. This is, because the AFM identifies the dysfunctional gene as the enemy within, inscribed on the genetic level. Consequently, any actions taken against it, is articulated as a positive, self-empowering action.

Through our research we learnt that the development of self-discipline in diets, safe sex practices, regular sports, forms of meditation, and psychotherapy seem particularly important in the experience of patient-users, especially of people living with HIV/AIDS. Some members of *Vivopositivo* have pointed out that this discourse on responsabilisation is socially enforced through the projection of guilt onto the person living with HIV/AIDS. According to one expert, this feeling is entangled with a deep anxiety regarding sex and morality. This may partly explain derogative cultural representations of people living with HIV/AIDS.

Vivopositivo questions this dominant morality and its cultural representations through highly contentious practices that articulate the personal as political. Similar to ‘coming out’ narratives (Plummer 1995), we found narrative formulations of identity that conveyed a sense of liberation in interviewee’s responses. Similar narratives of self-presentation are evident in individuals’ testimonies in *Vivopositivo*’s magazines, website, and public campaigns. These constitute fine examples of practices of self-government or practices of freedom. These practices empower people living with HIV/AIDS and promote an affirmative biopolitics.

These affirmative biopolitical strategies constitute opportunities to free the subject from social controls, oppressive regimes of truth and forms of undesired government. In our view, patient-user organization’s practices of freedom and self-government are good examples of an emerging affirmative biopolitics from below. As we have seen, patient-user organizations have successfully claimed a significant role in the field of (bio)medicine, health and illness. But how do they define the question of knowledge?

4.3 The Question of Knowledge

Although we agree with Foucaultians that science plays a crucial role in defining particular regimes of truth and causes significant social outcomes due to the disciplining effect of its claims of truth, this should not mean that regimes of truth are either unchangeable or immune to the blending of other discourses such as the activists’ discourse. Our case studies show that it would be misleading to understand the role of patients qua lay people as passive individuals that can only count “as a resource available for use, or an ally available for enrolment” for the benefit of what is too quickly assumed as the true driving force of scientific knowledge: the “entrepreneurial scientist” (Epstein 1995, 409). Science (and medicine), compared to other public arenas such as journalism, can be characterized as a less permeable and more enclosed system of communications. Nonetheless, groups like *Vivopositivo* and the AFM have advanced their own knowledge agendas and have influenced the constitutive rules of knowledge formation in medical science in their specific arenas. Hence, the common belief about the autonomy of science from other social spheres needs to be relativised. As seen here, the participation of the experience-based knowledge of patients and the strategic goals and values of organizations in producing and interpreting scientific knowledge has been effective.

How was this achieved? First, we have learned that patient-user organizations’ websites, documents and declarations frequently combine scientific affirmations, experience-based statements, advocacy statements and evaluations. This discursive hybridation allows them to redefine

some key aspects of the field of medical discourse. The hegemonic biomedical discourse is forced to introduce new elements into its articulation, thus changing its identity. Therefore, the sharp distinction established between specialized biomedical knowledge and lay knowledge is insufficient to describe the discourses of our cases.

To different degrees, both the AFM and Vivopositivo have been critical of the pure biomedical paradigm due to the hierarchical relations it imposes on the field of medicine and illness. This oppositional critique is a second mechanism by which the above mentioned sharp discursive distinctions become relativised.

Patient-user organizations participate in defining the meaning of health and illness discursively in a complex relationship with hegemonic medical authorities. This relationship cannot be described as a mere rejection of such authority. Activists influence the production of knowledge “through amassing different forms of credibility” and “can in certain circumstances become genuine participants in the construction of scientific knowledge”. Thus, “within definite limits” potentially they can “effect changes both in the epistemic practices of biomedical research and in the therapeutic techniques of medical care” (Epstein 1995, 409).

A fourth mechanism, related to the previous points, is the acquisition of cultural competence on part of the patient. For instance, the AFM built upon the knowledge of patients as both active agents of their condition and co-participants in the process of knowledge production. Today, they claim their knowledge is as worthwhile as that of scientific experts.¹¹

A fifth mechanism is the use of scientific knowledge for the sake of the organization’s strategic goals. The AFM, for instance, formed the R&D company Généthon after concluding that state support was inadequate for rare disease research, and strategically decided to participate in genetic research, involving itself in general research policy and genetic research since the mid-1980s (Rabeharisoa/Callon 1999). Although the AFM’s devotion to genetic research is articulated for the benefit of its clientele who live with rare diseases, its research policy is not limited to them alone. The logic behind its policy is that all kinds of genetic research will prove useful for patients in general and therefore needs to be fostered.

Among the many activities of the AFM, we would like to highlight the practice of biobanking – the organized collection of biological material such as blood or tissue and associated data. The AFM concluded that biomedical research lacked both quality and quantity of biological material and so started its biobanking activities in 1990. Since then, an AFM employee explains, it has organized sampling campaigns and started several DNA banks for the storage of human biological material. The Généthon DNA and Cell Bank, for instance, is a rather particular category of biobank because it has been founded, financed and governed by the AFM. Furthermore, its activities are completely aligned with the goals, values, mission and biomedical research endeavours of the AFM. If one accepts the power of genetic research, biobanking may be considered not only as another means to fight disease but also as an empowering practice. Consequently, the corporate identity of the biobank is defined by the determination of the AFM to find a cure for rare genetic diseases by all means and its refusal to accept disease as an inevitable fate. Ultimately, the biobank updates the concept of biological citizenship precisely because it puts the refusal to accept disease as a final verdict into practice, by fostering hope and encouraging social struggle (Mayrhofer 2008).

In contrast, Vivopositivo seems more critical of the promises of medical research. In some of its publications and documents, Vivopositivo has been sceptical regarding the suitability of the biomedical approach to HIV/AIDS altogether arguing that it fails to take into account the individual and his/her psychological and social milieu as a whole (Zambra et. al 2004; Vidal

2007). Key members of Vivopositivo have informed us that they have strategically fostered a policy of producing their own knowledge, but without confronting the issue of drug therapy. Vivopositivo's leaders have realized the power of gaining public awareness and scientific credibility in matters related to the psychological and social aspects of their condition. It has been difficult for them to get financial support for research purposes, probably because they are a socially stigmatized group. The support provided by The Global Fund to Fight AIDS, Tuberculosis and Malaria (a UN fund for the struggle against epidemic illnesses) has been crucial in this. The knowledge produced by Vivopositivo has a particular focus on problems of social exclusion based on gender/sex, discrimination, stigma and equitable access to health care, social and cultural representations of people living with HIV/AIDS, and school teachers' perceptions of people living with HIV/AIDS. Publications supported by Vivopositivo have become important legitimizing mechanisms for government and authorities in the health care sector. Moreover, these publications have generated a feeling of self-esteem among local leaders of Vivopositivo as they grant them legitimacy as experts on their own condition who are thus able to speak to medical doctors as "equals".

To some extent, the two organizations considered in this study use science – the AFM biomedical science, Vivopositivo critical social science – to democratize the production of knowledge, and engage effectively in specialized debates. Our study shows that there is no deterministic way of achieving this. Whereas some organizations might support current medical research and establish joint efforts with biomedical teams (Novas 2006; Rabeharisoa 2003; Rose 2006), others might continuously challenge medical knowledge and authority (Epstein 1996). Health social movements and patient-user organizations have developed a wide range of forms of knowledge (production) and social alliances in order to acquire credibility of their own. The identity of these organizations is not only defined by the way they relate to medical knowledge, but also of paramount importance is how they define the disease or condition, which we discuss in the following section.

4.4 Creating Public Awareness: Hope and A Struggle Against Disease

Creating public awareness is a complex process that comprises concrete activities in order to a) make the illness visible to a wider audience, b) appeal to the public in order to gain its solidarity and to foster their identification with its sufferers and c) promote the transformation of a personal or constituency-based issue into a political problem for the whole society in order to pursue common and/or more global solutions.

We have found a common discursive trope in both organizations that help them to construct public awareness: the representation of the disease as the enemy and the patient as a warrior facing his or her illness in an on-going struggle, but who will nevertheless be victorious in an undetermined future. We think that the symbolic field set up by both organizations is similar and is defined by a series of warfare-like figures that are used to rhetorically define and somehow portray the agonistic experience of the ill. This discourse positions 'patients' as people who resist, as active biological citizens who demand and warriors who fight for self-determination and freedom. The goal to find a cure is to be achieved through self-governing practices that should liberate the 'patient' from their biological determination.

Consider, for instance, the empowering campaigns of the AFM Téléthron fundraising event that present the ill person as a proactive agent who "fights against ignorance and marginalisation",

convinced that “a cure is possible” (see plate 1). Therein, the image of the innocent child as a warrior fighting against an (inner) enemy is repeatedly conjured up in order to muster support. Thus, although the warrior is not a religiously motivated virgin fighting against the Britons, the comparison with Jean d’Arc seems accurate, as the fight against neuromuscular disease is exemplified by the image of an innocent child, motivated by a higher cause to continue in the battle against a mighty enemy and determined never to give up (Mayrhofer 2008; Mayrhofer 2010).

Similarly, Vivopositivo promotes the figure of the person living with HIV/AIDS as a proactive individual who fights against disease, promotes self-care practices and openly faces his or her condition in society in order to overcome stigmatization. We believe that all these figures of struggle are sustained by an ethos of hope.

Nik Brown states that “hope serves to designate a vocabulary of survival where survival itself is at stake” (quoted in Novas 2006, 291). We agree with Carlos Novas, who identifies an affinity between the language of activism and the language of science: both of them indicate a “willingness to overcome obstacles, transcend limits and explore new horizons” (Novas 2006, 291). Both language games point towards an achievable future through the use of imagination, including fantasy and dream work, scientific categories and research, and political ideas and transformative action. Both language games also aim at intervening in history and have a concept of a manageable future. Maybe the crucial aspect is the productive merging of personal suffering and hope through a collective project. In these discourses hope and suffering come hand in hand and contaminate one another. People are mobilized by the promises of biomedical research for a better future and a cure. As we will show, the element of hope is also applied in public campaigns aimed at creating public awareness of the disease.



Plate 1: Excerpt of poster “14 Years of Téléthon”, exemplarily showing six Téléthon campaign posters, photo by M. Mayrhofer, 23. 12. 2009.



Plate 2: One of the postcards from the 2007 preventive public campaign “Póntelo en la dura, usa condón”

For its part, Vivopositivo also promotes a number of activities to generate public awareness of the disease. It takes part in the design and decision-making process behind the preventive public campaigns run by CONASIDA, the Chilean state agency in charge of the struggle against HIV/AIDS. Because these campaigns have been contested by the Catholic Church and conservative groups, Vivopositivo also promotes its own campaigns. In 2007, for instance, posters and collectable postcards promoting the use of condoms were freely distributed in three important regions of the country from postcard shelves located in bars, restaurants and other public venues. The postcard reproduced below “Póntelo en la Dura” is illustrative of this.¹²

Another interesting example of public awareness campaigning is a yearly Candlelight Vigil in remembrance of those who died of HIV/AIDS. We wish to highlight that this event takes the form of a religious ritual: the vigil begins with a procession to a major religious temple where a keynote speaker typically addresses the public. Some mottos used since 2004 are exemplarily: “For those who died of HIV/AIDS”; “Lighting the path towards a brighter future”; “If you remember you act”; “Keep the memory of those who died from HIV/AIDS alive”. Most of these represent the organization’s fight against forgetfulness and stigma. They convey a positive sense of hope for a better future and an active commitment to remembering. Thus, the situation of the AFM is quite different in regards to public representation as it does not fight against stigmatization but “against oblivion and indifference”, as it states on its website and brochures. Creating public awareness of this illness is a crucial step in the organization’s fund raising activities. Once such public awareness is reached, organizations can capitalise on it for both raising funds and political awareness.

5. Common and distinctive features of the AFM and Vivopositivo

Thus, which are the common features of the AFM and Vivopositivo? To begin with, both patient-user organizations are constituted as politicised collective illness identities. They promote active involvement of patients using the language game of citizenship and rights and they question biomedical knowledge and authority, although in different ways and degrees. Moreover, these patient-user organizations mobilize a strong rhetoric of struggle against the disease to account for the experience of the predetermined individual (e.g., carrier of a particular disease gene) or the active (self-empowered) “patient”. Furthermore, the AFM and Vivopositivo build their respective collective identities around identifications with the collective sharing of suffering and, most importantly, hope. Especially this notion of hope seems to be a condition of possibility for the articulation of self-empowered scientific and activist discourses. In turn, these new discourses seem crucial to the formation of biological citizenship and the formation of politicised collective illness identities.

Nonetheless, one should be cautious about over-emphasizing the positive aspects of hope in relation to an ethos of empowerment. Indeed, this ethos of empowerment relates to two risks: on the one hand, falling into a teleological, progressive and evolutionary narrative and, on the other hand, becoming functional to neoliberal governmentality and the privatisation of public responsibilities. That said, it might not be surprising that patient-user organizations are becoming stronger due to the retreat of the state from such matters.

Furthermore, the AFM and Vivopositivo have in common that they both foster public awareness in order to gain public visibility, recognition and, thus, to create political opportunities for pursuing their strategic goals. In doing so, both organizations deal with the challenge of constituting the sick person as a self-empowered citizen, who has both the right and obligation to improve his/her own health through a variety of techniques that work upon his/her own body and psyche (which are not necessarily part of the hegemonic scientific discourse).

As yet another common feature of both organizations we identified the trend towards constituting a new power/knowledge configuration. By power/knowledge configuration we mean the entangled and concrete form that the articulation of power and knowledge historically takes. There is a variety of potential power/knowledge configurations that can co-exist in the field of biopower in contemporary societies. Nevertheless, two such configurations are relevant for us. On the one hand, a science-centric power/knowledge configuration because it erects a deep divide between scientific and lay knowledge cultures and, on the other hand, an emerging biological citizen-centric and participatory configuration because it relativizes the distinction between expert and lay knowledge. As far as our research is concerned, we are convinced that both our case studies exemplify a transformation of the hegemonic science-centric configuration, allowing a new power/knowledge configuration to emerge that counters its hegemony. This new configuration seems to be conflictive and criss-crossed by tensions that call for more detailed case-specific analyses. Nonetheless, it seems to us that we can already speculate about two main poles in this tension: (1) scientific discourses such as biomedicine, genomics, public health and public policy and the(ir) respective regimes of truth and forms of subjectivation *and* (2) the radical political discourses of patient-user organizations and unprecedented understandings of identity, citizenship and politics that empower people through forms of self-governance and practices of freedom that are constitutive of biological citizenship.

Certainly, in both cases we have found sufficient evidence of the emergence of what can be called a “politicised collective illness identity” that has been formed through a web of relations,

discourses, subjectivation technologies and institutional strategies. Thus, the AFM and Vivopositivo have become key players in the realm of biopower in their respective immediate arenas and countries. They have been able to influence – or even sometimes change – the way “patients” understand their position and relation to their physician, knowledge, disease/condition and biomedical research. Perhaps most importantly, they have influenced communities of “patients” by gathering people with similar problems and experiences, providing mutual support and opportunities for peer-counselling, and by establishing links and exchanges frequently through new media. They have also become key political actors, playing the role of well informed and socially accepted representatives of both their clientele and the (bio)political establishment. In addition, they have been able to influence public health design, provision and research funding to a certain degree. Last but not least, patient-user organizations positively re-frame the notions of healthy and ill persons by detaching their partisans from associations of suffering and fate, and by re-introducing the idea of hope and an open future for the broader community.

All the previous common features highlight important similarities. Nevertheless, there are also significant differences between the two organizations, which we do not want to ignore in this article. At first their respective institutional and financial strengths are very different, leaving Vivopositivo in a far more vulnerable and less institutionalised stage than the AFM, which can rely on its *Téléthon* funds. Also, it needs to be recognized that the particularities of the illnesses they advocate for are very different indeed, both socially and medically. Finally, it seems to us that each organization analysed here pertains to different regimes of the self. Although Vivopositivo has a wide range of strategic goals ranging from state recognition to public awareness, we consider that its emphasis lies on state recognition, improving access to treatment and obtaining financial support from the state. It is also more radical in its critique of the external loci of power and critical of the structural determinants surrounding the condition, such as the discrimination and exclusion of gay men and sex workers. In contrast, the AFM seems to position itself as less critical of the medical establishment and the state, perhaps acting more confidently because of its access to extensive financial resources raised by *Téléthon*.

6. Conclusion

Biological citizenship is an emerging political identity that has arisen out of a discourse on citizenship that, in certain contexts such as patient-user organizations, re-interprets patients’ relationships with their own biological bodies as citizens. Both our case studies showed that biological citizenship has contributed to contentious politics in the field of health and illness in recent decades by renewing the discourse on these matters.

The involvement of AFM in biomedical and genetic research and the production of critical social research on HIV/AIDS by Vivopositivo constitute empowering modalities of knowledge production and practices of freedom and self-governance. These practices contribute to the re-framing of hegemonic categorizations of illness and health, passive patients and active biological citizens.

There is an emerging configuration of power/knowledge that combines forms of scientific discourse with politically inspired discourses that tend to empower the patient as a biological citizen. Biological citizens are members of imagined communities that cohere around the experience of having a certain condition. Moreover, their solidarity is also the effect of a hope for the future, partly represented by investment in medical and biotechnological innovation.

We claim that patient organizations are built from a web of relations that, firstly, includes a variety of discourses (such as the scientific discourse, public policy discourses, common sense representations of groups in public discourse, and patient-user organization discourses) that frame the identity of patient-user organizations. Moreover, we claim that the socio-political identities of patient-user organizations are constructed relationally within a web of interactions with other organizational structures, such as: the state, the public health system, the media, the biomedical industry, expert organizations, medical science, the patients, relatives, etc. Also, we have demonstrated in this article that the strategies or logics of the interests involved are of paramount importance in framing the identities of patient-user organizations. Here we focused on the analysis of the principles and values of patient-user organizations, such as self-help (e.g., mutual-help patients' groups), the promotion of quasi-political interests and practices of freedom (e.g., self-understanding and self-governance by activist and participative patient groups).¹³

Finally, we conclude that the emergence of a biological citizenship is related to – and somehow the result of – the work of patient-user organizations. Biological citizenship is a new expression of citizenship that takes place in the realm of biopower due to the changes brought about by patient-user organizations. However, this does not mean that we consider that patient-user organizations and biological citizenship are responsible for all changes affecting the realm of health and illness. Of course there are other factors, some of which can be regarded as very significant in the structuring of the contemporary field, such as the constitution of a bio-capitalist economy and the introduction and translation of new revolutionary technologies in biomedicine. Our claim is more humble. We suggest a focus on patient-user organizations because a small but very meaningful part of the current changes in the field can be explained by exploring the intricate articulation between the old configuration of power/knowledge and these new types of organizations that introduce new practices of knowledge, thereby producing what we think is a more complex power/knowledge configuration of affirmative biopolitics.

NOTES

- 1 Paul Rabinow's concept of "biosociality" refers to the transformative condition under which both nature and scientific work become increasingly revealed as cultural practices.
- 2 For the AFM and G n thon, more than a dozen interviews were conducted with key personnel. Among them Bernard Barataud, former director of the AFM and director of G n thon. The names of further interviewees are confidential. For Vivopositivo, we conducted twelve interviews with regional and national leaders. Their names are confidential.
- 3 We found some Foucaultian conceptual tools were useful in order to explain the dynamics of control visible in the field of health and illness and the contentious strategies of patient-user organization. Nevertheless, we want to make clear from the start that we depart from Foucault in significant matter. His analysis of biopolitics is extremely illuminating of the control of populations exercised by power. Unfortunately, he did not say much about resistance to biopolitics and counter-power. We develop the notion of affirmative biopolitics in order to supplement Foucault's concepts.
- 4 Rose and Novas (Rose/Novas 2005) were among the first authors to firmly establish the term biological citizen(ship) in the field of health studies. In his recent work, Nikolas Rose (2006) expands this beyond the purely genetic and somatic. We prefer this new version, more in line with the argument of other writers on the topic (such as Petryna 2002; Petryna 2004), who see in the biological citizen a form of political identity coined in the language of citizenship, rights and political claims.
- 5 The empowerment of patient-user organizations has been well documented by many. For our study, Epstein (1995), Petryna (2002; 2004), Rabeharisoa and Callon (1999) and Rose (2006) are the most relevant.
- 6 We use the term biomedical establishment to refer to the mainstream medical institutions, discourse and social hierarchies.
- 7 The French T l thon is a 30 hours fund-raising festival that is yearly broadcasted on French television since 1986. It employs a warlike rhetoric in its campaigns.

- 8 <http://www.vivopositivo.cl/php/home.php.html> (accessed: 1.5. 2007).
- 9 Regarding this see <http://www.ipsnews.net/2010/10/chile-women-sterilised-over-hiv-status/> and <http://www.ipsnews.net/2008/11/chile-512-hiv-positive-people-not-notified/> (accessed: 1.10. 2011).
- 10 According to one expert, this seems more common in rural areas of Chile.
- 11 The AFM encouraged this simply because it was a basic necessity for survival. Parents needed to take care of their children and learn to live with their diseases since there was no cure and doctors were not knowledgeable or even aware of such rare diseases, some of which did not even have a name. Epstein (1995) and Novas (2006) make similar points.
- 12 The postcards depicted images of overtly sexual content that became controversial precisely because of their open message. Visual messages where oriented to a variety of audiences between aged between 20 and 49, thus, not only addressing those who are the “usual suspects” such as the gay community, but the general (sexually active) public.
- 13 Other logics are also relevant and should be explored in research to come. Among those, we find the profit-making logic of biomedical markets/private laboratories and the disciplinary and control oriented logic of the state or combinations of these two logics especially interesting.

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AUTHORS

Hernán Cuevas VALENZUELA (PhD, Essex University, UK) is Lecturer in the School of Political Science, Universidad Diego Portales, Santiago de Chile. His research on Vivopositivo has been made possible thanks to a FONDECYT grant (Project 11080249 “Biological Citizenship”).

Michaela Th. MAYRHOFER (PhD, University of Vienna/EHESS, France): The research contribution of Michaela Theresia Mayrhofer originated within the framework of a project on “Transforming Health Policy: Biobanks, Pharmacogenetics/Pharmacogenomics and the Governance of Bio-medical Research” funded by the GEN-AU (Genome Research in Austria) Program of the Austrian Federal Ministry for Science and Research (<http://www.gen-au.at>). Furthermore, the completion of her work was facilitated by the following grants: the Brocher Foundation Fellowship (2007), and two scholarships of the University of Vienna (the “F146-S Forschungsstipendium” and the “Stipendium für kurzfristige wissenschaftliche Aufenthalte im Ausland”, both 2007). Academically, the work benefited from several stays at the Centre de recherche médecine, sciences, santé et société (CERMES) CNRS UMR 8169 – Inserm U750 CERMES (2004–2007) in France. Finally, the Medical University of Graz supported this publication with the “8. März Stipendium”.