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# Identity, Representations, and Beliefs: HIV Controllers Living on the Frontier of Good Health and Illness

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## Abstract

Some people living with HIV spontaneously control the virus without antiretroviral treatment. They are called HIV controllers, and their status places them at the limits of bio-clinical normality. The objective of this study was to investigate HIV controllers' beliefs and representations of their individual trajectories using a qualitative approach. Fourteen HIV controllers were interviewed. Vertical analysis focused on examining how interviewees' specific beliefs and representational processes help these patients adapt to their particular situation. Horizontal analysis focused on how patients' biographic trajectories and identity positioning help them make sense of their situation. Results highlighted that perceiving oneself to be healthy or ill was linked to change or a lack of change in terms of disease perception, beliefs, and representations, when seropositivity was announced. This study of social representations and the processes involved provide crucial elements for health professionals caring for HIV controllers.

## Keywords

HIV/AIDS; qualitative research; biographical analysis; social identity

## Introduction

In 2004, a medical team discovered that a woman infected with HIV for more than 10 years had an undetectable viral load despite HIV DNA being found in her CD4 cells. Lambotte subsequently defined “HIV controllers” as patients (a) infected for more than 10 years, (b) never having received antiretroviral treatment (except during pregnancy to avoid mother-to-child transmission), (c) with over 90% of RNA plasma viral load measurements under 400 RNA copies/ml (Lambotte et al., 2005; Potter et al., 2007), and (d) with CD8 and CD4 lymphocytes counts demonstrating the virus is being controlled (Lambotte et al., 2005; Potter et al., 2007; Sáez-Ciri3n et al., 2007). Biological data analysis underlined the possibility that genetics played a role in this unusual occurrence, in particular the possible overrepresentation of certain Human Leucocyte Antigen (HLA) alleles (Deeks & Walker, 2007). HIV controllers are rare, accounting for less than 1% of HIV-infected patients (Lambotte et al., 2005). They have been identified in Europe, United States, Japan, and elsewhere, and the modes of HIV transmission in the population have been comprehensively described. Innate immunity, involved in the first

steps of primary infection, has also been investigated (Lambotte, 2012).

The discovery of HIV controllers encouraged scientists to start investigating biological disorders brought to light through technological progress, especially “socially invisible” asymptomatic biological disorders (Lonardi, 2007).

From a psychological and psychosocial viewpoint, previous studies provided great insight into the lives of long-term asymptomatic patients (LTA) suffering from chronic pathologies (Crossley, 1998; Davies, 1997;

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Pierret, 2001). Yet these studies were performed before the advent of highly active antiretroviral therapy (HAART) and the subsequent radical evolution of HIV care. Initial research work on HIV controllers has not benefited from renewed interest, and publications are few in number. When searching for the keyword “HIV-controllers” in titles or abstracts in the ScienceDirect and Medline databases, only 64 articles with peer reviews were observed from 1997 to 2015 for ScienceDirect, and 73 for Medline. All these articles are linked to virological or clinical research but none refer to patients’ daily-life experiences, identity, quality of life, or to their beliefs and representations associated with their special status.

In another context, asymptomatic cancer patients, tested early for cervical cancer (Martínez, 2005), were described as women “living on the frontier of health and illness.” HIV controllers do not experience any of the classic symptoms of HIV. Investigating how they position their seropositivity and their particular status to live with the disease in their daily lives constitutes a valuable research objective (Baszanger, 1986). Such research would entail asking them specific questions about their daily lives to collect both their own explanations for and the sense which they give to their personal experience, something we will define as their “interior vision.”

This personal experience is established through the discourse of the subject’s biography. Biography is defined as a staging of a system of thought relating a person’s life, not in chronological or event order, but in an order specific to each person in terms of singular events (Desclos, 2002).

Such research would also fuel reflection on the theory of biographical disruption (Bury, 1982; Ciambone, 2001; Ezzy, 2000; Lonardi, 2007; Wilson, 2007), which suggests that a biological crisis arising from a chronic pathology leads to disorders in everyday life and difficulties with social insertion (Bury, 1982). Biographical disruption inevitably leads to a new type of relationship with time, be it the present, past, or future (Mendès-Leite & Banens, 2006).

According to Bury (1982), the experience of chronic illness disrupts the structures of everyday life and the types of knowledge that underpin them, projecting the person into a world that is only seen as distant in the biographical line of the individual. Future plans must also be reviewed. In this way, he conceptualizes biographical disruption, defining it according to three aspects. The first of these is a break in behaviors previously acquired and taken for granted by the subject. The second is a profound break in the explanatory systems normally used by the person, that is to say, it is necessary to completely rethink the notion of biography for the subject and the associated concept of oneself. The third aspect is an evaluation of the resources mobilized to deal with the present situation.

This biographical disruption, marked by a chronic disease, seems to be followed by a type of “biographical effort” (Corbin & Strauss, 1987), the objective being to cope with this new situation. This effort involves recomposing one’s identity, something which Pierret describes as “biographical reinforcement” (Pierret, 1997) between past identity before the disease and the current identity of the “sick person” to move toward a positive identity of the ill person (Herzlich & Pierret, 1984). To do this, the resources mobilized to deal with this disruption are cognitive and material in type (Bury, 1982). “This situation requires a constant effort of biographical reconstruction and negotiation with oneself, in order to give coherence to one’s identity which has been changed by the onset of the disease” (Pierret 1997).

In this study, we used social identity theory, a component of identity theory, which stems from the feeling of belonging to a certain social group (Tajfel & Turner, 1986), to provide potential keys to understand HIV controllers’ choices regarding social positioning. More than for other diseases, HIV is perceived as affecting specific populations because of its modes of transmission. HIV-positive social groups have historically been stigmatized because of this. Accordingly, HIV controllers may position themselves in different roles, depending on their individual experience with the disease and on social response to their individual situation. Understanding whether HIV controllers consider themselves ill or not, and investigating what elements, in their opinion, constitute disease symptoms, is of important research value.

The theoretical framework of social representations (Moscovici, 1961) provides a sound reference point to investigate HIV controllers’ constructions of sense regarding their specific situation. Social representations are based on common sense knowledge and are constructed in the social space to help understand the world around us (Jodelet, 2006). HIV/AIDS social representations are numerous. They influence people living with HIV (PLHIV) and HIV controllers’ daily-life experience and identity. Kleinman suggested that a disease gives rise to three types of representations: a biomedical event (disease), a subjective experience (illness), and social and cultural representations (sickness; Kleinman, 1980, 1988). HIV controllers are in a particular situation as their disease experience does not correspond to standard disease-related social representations and expectations. Although general social discourses (sickness) about HIV do not correspond to the particular experience of HIV controllers, they probably have an impact on the sense that HIV controllers give to their own life experience. Jodelet highlighted the influence of social representations on the sense of life experience, in terms of the perception of one’s own body (Jodelet, 2006).

The objective of our study was to acquire a greater understanding of the impact of HIV controller status on patients' quality of life, and to help providers in the follow-up of this population. HIV controllers' specific situation deserves further exploration of their life experience to understand how they live with HIV. In this study, we investigate how these people deal with incoherence.

## Method

We used a qualitative methodology based on two major elements to study the daily experience of HIV controllers living with HIV in France. First, we studied social representations, knowledge construction, social thought, and identity construction (Flick, 2001), which helped us understand the complexity of these phenomena. Second, we used a field-based exploratory qualitative approach which helped us discover the day-to-day reality of individual patients. Our research project is an ancillary study of the ANRS CO (COhorte) 18 HIV-controller cohort. All patients in our study were included and followed in this cohort.

The interviews were performed in eight different cities in France. The physician or the clinical research assistant of the hospital following the patient during a medical visit recruited study participants. If the patient agreed to participate, he/she was provided with the interviewing researcher's phone number to fix an appointment. The location of the interview was chosen by the patient (at home, hospital, working place, other). Audio recording of the interviews were made to help subsequent transcription and to avoid memory bias. One person performed all the interviews. She is a co-author of this article, and has a master's degree in social health psychology (M.M.).

This study was approved by the consultative committee for the treatment of medical information (CCTIRS in French), number 2011-1159, and the French data protection authority (CNIL in French), DR-2012-658. Written informed consent before enrollment was mandatory. All data were confidential.

## Data Collection

The HIV-controller study group comprised 186 patients. Among them, 51% were women and the median age at the inclusion was 46 years (19–78). This fell to 45 years for those who completed the social sciences questionnaire in this study ( $N = 96$ ). This compares with 48 years in the ANRS VESPA study, which is a cross-sectional survey representative of the French population of HIV-positive individuals (Lert et al., 2013).

Accordingly, even though the qualitative methodology used is not representative, it is consistent with existing data on the French HIV population. Data collection

occurred between 2009 and 2012. The interviewer (M.M.) was trained in qualitative research techniques. Participant numbers were calculated based on Glaser and Strauss's data saturation method (Glaser & Strauss, 1967), where theoretical saturation occurs when the researchers judge there is no need to collect further data as no new properties of categories can be constructed and, ideally, when a basic social process has been identified (Wiener, 2007).

The biographical interviews took into account the life trajectory of interviewees, and consequently helped to both highlight possible biographical disruptions arising from seropositivity and capture possible changes occurring throughout the HIV controller's life. The opening question in each interview was "Tell me about your life since becoming aware of your seropositivity." This open-ended questioning style dominated the interview, whereby relevant interview questions were only asked if the patient did not spontaneously speak of the issues of research interest in their account. The interview process was followed by an iterative decoding process (questionnaire development and data analysis) and finally an inductive analysis (developed a framework through open coding of data).

Interview guidelines were adapted after each interview, if deemed necessary, to integrate emerging themes deserving further investigation. Data collection processes used theoretical sampling, in which an emerging theory is further explored by deliberately seeking out new participants with characteristics that may expand or challenge the theory.

Biographical interviews with HIV controllers were performed to investigate different orders of reality (Bertaux, 2001), examining not only interviewees' real-life experience and how they perceived this experience, but also how they thought retrospectively about their life trajectory. Such interviews also involved a discursive reality, that is to say, the way individuals talk about their life trajectory. We took these different levels of reality into account during interview analysis to try and explain the information and meanings which were relevant to the study objectives (Demazière & Dubar, 1997).

## Data Analyses

The qualitative approach entailed a vertical and horizontal analysis of the collected data and enabled us to first compare individual experiences of participating HIV controllers with their biographical experiences, and then to compare documented experiences between different HIV controllers. We performed a vertical and then a horizontal thematic analysis to systematically identify the different themes appearing in each interview, that is, the different units of meaning that made sense to the interviewee (Bardin, 2005). We used methodologies employed in the

**Table 1.** Sex Profile of Patients Interviewed.

Sex	Sexual Orientation	Partner(s)	Age	Year of Diagnosis	Child(ren)
Men	Homosexual	No	50	1989	No
			51	2002	Yes
		Steady + Casual	49	1992	No
			57	1985	No
			44	2006	No
	Heterosexual	Casual	48	2008	No
			41	2000	No
		Married	71	1992	Yes
			47	1987	Yes
			45	1986	Yes
Women	Heterosexual	Steady	35	1996	No
			33	1997	Yes
		Married	52	1985	Yes
			47	1993	No

context of interpretative phenomenological studies (Smith, cited by Apostolidis, 2003). In the first phase of “immersion [into] and familiarization [with]” (Apostolidis, 2003, p. 22) the data, exploratory coding of all the interviews was performed to distinguish between the themes arising during the interviews. The second phase entailed the creation of an “inventory and [a] systematic identification of themes emerging from the corpus” (Apostolidis, 2003, p. 22). An analysis chart was then constructed and applied to each interview. This enabled us to highlight the thematic categories in conjunction with the various connections revealed. The interview-based qualitative approach we use here does not aim to be representative of the population through the use of a large number of interviewees, but rather through the collection of high-quality data, collected to understand and comprehensively analyze the daily-life experience of interviewees and the meaning which they give to their special status.

## Results

Fourteen HIV controllers were interviewed. Seven men described themselves as homosexual. Six HIV controllers had at least one child. Eight participants were diagnosed with HIV before 1996. Eleven had a steady sexual partner or were married, five declared having occasional partners, and two declared they had no partner (Table 1). The diversity of socio-demographic characteristics in the study sample enabled us to investigate a wide range of experiences.

The vertical axis analysis involved representations relative to HIV infection and the HIV controllers’ specific beliefs about their situation. Exploring these representations increased our understanding about how representational processes allow HIV controllers to adapt to their particular situation. The horizontal analysis focused on the participants’ biographic trajectories and the identity

positioning which they constructed to help them make sense of their experience.

All the quotations presented below are from the HIV controllers interviewed.

Results are organized around four themes, each one subdivided into more specific categories.

### *Representation of HIV/AIDS: Construction of Hope*

HIV controllers are first and foremost PLHIV, whose social representations have largely been constructed by elements creating stereotypes (more specifically social discourse and the negative image surrounding HIV), and on the initial image of HIV as a disease leading to certain death:

I think so. There’s the treatment to take, the symptoms . . . no, it can’t be easy for them. Even psychologically, especially psychologically. I mean it’s a disease that we heard about in the 1980s. So, like, I heard about it at the beginning of the 80s. At that time, we said, like, it was a really horrible disease. (Woman)

With the advent of HAART, HIV was regarded by the media as a chronic disease which could be managed quite well. Medical discourse supported this idea:

Because they want to sell you the idea that you are chronically ill just like the others, yeah right, it’s not the case. [ . . . ] It’s always the same logic of euphemisation of the problem and I think plenty of guys who’ve been on triple therapy for 20 years etc. would show you that. Maybe guys [susceptible to infection] should pay more attention to what they do. (Man)

Regarding the word “medical,” the study’s interviewees explained that when they were diagnosed at the beginning of the epidemic, doctors knew very little about HIV.

Certain death was often mentioned, reflecting social discourse at the time:

At the beginning it was a little tough because at the start people would say, like, even the doctors would say 5 to 6 or 7 years [ . . . ]. Even the professionals I think, at that time, in 84, 85, I think they were . . . I remember times when I saw guys who didn't know any more than the patient. (Man)

Half of the interviewees had lost close friends because of HIV. Some talked about hospital visits, about the state of those who were ill with severe symptoms, skinniness, tiredness, body transformation, treatment side effects, and huge losses of friends due to the disease, as well as pain and the shock of death:

At the time, they didn't want to accept people in emergency units in extreme distress so he died on a simple hospital bed in C. where I went. And he was a remarkable man, the emergency unit didn't want to save him. So he died like a piglet that you cut open. (Woman)

For some HIV controllers, life for a seropositive person is not always easy today, despite treatment: difficulties entering the job market, treatment side effects, and physical scars. Instead, others clearly expressed that living with HIV is much easier today:

Because it's true, there are fewer and fewer deaths with this disease. Before 1996 yes, we talked a lot about death, it's true yes. Now a treatment exists, [there are] advances. (Woman)

Symptoms are less present, people hardly ever die from AIDS, and there are far fewer long-term hospital stays. Life with HIV is considered "normal." Treatments have fewer side effects and are less restrictive:

Yes. Before, when there was AIDS, when people took treatment they often had diarrhea. I saw that on TV and now that's really changed and there's hardly any more of that. Patients live a lot better now. There's a lot of research. (Man)

Positivity is increased by the hope of a future remedy which could cure the disease permanently or at least control it:

One day they'll manage to find medicines where people will feel better, or where it's more accepted in society. I tell myself, "I'll open the door a little more, I'll talk about it." But for the moment that's not the case. (Man)

### *Beliefs and Feelings of Control*

Medical knowledge about controlling the virus is limited. Consequently, HIV controllers need to find other keys to understand their situation. In this context, the various

interviews provided different and sometimes overlapping explanations.

*Mind-set and healthy lifestyle, having control over the disease.* A large majority of interviewees underlined the importance of mind-set in terms of not falling ill. Some reported that they decided right from the start that the disease would not "drag them down." Having a "fighting" character and staying "cool-headed" were also highlighted. Some said people should not let themselves be "closed in" by the disease:

No, first there is work on oneself; I have a conception of life that makes it hard for me to see why I would ever go down that path [of letting the disease destroy him]. I think many people have this problem when they're told: "You are seropositive," that's it, it's over, nothing more can be done. For me, when I said: "I will never be sick," they tried to get me to understand that no, in fact I would be sick. You just need to be a little weak and you'll fall in there: "That's it, it's over, I'm going to be sick. I'm going to have to take medicine." It's a little like cancer: "That's it. I'm going to die." And then, there's no more fight in you, be it physical or any other type, you let yourself be taken down the road of the disease. So for me, that, no way. (Man)

Four mentioned the importance of a healthy lifestyle. This included eating well, practicing sport, and taking care of oneself. One patient also mentioned the importance of not becoming super-infected.

### *Religion and Spirituality, Partial Control*

Three interviewees mentioned their relationship with God, prayer, and the belief of being chosen or "born under a lucky star." One of these three did not understand why he had been chosen:

So touch wood, maybe I was born under a lucky star . . . (Man)

I've been, well [ . . . ] I've been to Lourdes four times, yes, I've practiced my religion, I was even in the French boys scouts. [ . . . ] I can say, I pray to God thanking him for how I am because it's true . . . yes indeed [ . . . ]. Yes, I've been to Lourdes five times already, even my daughter the last time we went there said—and you know there are a lot of plaques of those who've been cured and all that—and she said to me "you should make yourself one because you're cured now!" (Man)

One of the 14 interviewees had seen a witch doctor for hepatitis infection and said that perhaps doing so had had a positive effect on HIV disease progression. Another explained that he had his own personal psychological support technique and that he used plants to treat himself.

*Strong immune system, weaker virus, a comprehensive understanding of scientific knowledge.* A large proportion of those interviewed had a comprehensive understanding of the scientific discourse and explained their status in terms of their particularly strong immune system. One even talked about his resistance to other diseases before talking about HIV:

I was also sick several times when I was a kid, an adolescent, young adult, and each time without medicine, the illness wasn't diagnosed they told me they were parasite-based illnesses, and each time my immune system was really, really strong. [ . . . ] So between these episodes, during childhood to adolescence and then these episodes in my sexual adult life, each time I, how can I put it, my body reacted, and often without medicine. (Man)

Two others spoke about the immune systems of family members or people from their region of origin:

And another thing about my family, in my family everyone dies really old. I don't know if that's useful but let's say everyone really old even my grandmother who died relatively young, she was 88. [ . . . ] And in the valley where we live, lots of people die really really old, [ . . . ] so there are characteristics, I don't know, that are specific to our family, our valley, our group. (Man)

One patient believed that being a HIV controller made him more resistant to other diseases:

The last time I talked about it also to X, the fact of being a Controller, I think we're more capable at fighting as well. Maybe for other viruses, other things, the body is stronger at fighting too . . . , I think as well. Because I work a lot in the humanitarian field and I've travelled a lot to Madagascar, the Comoros where there's malaria. I've never taken medicine because I'm anti-medicine. I mean, sometimes I get a temperature but like nothing more than that. I think that it's as if you had immunity against other things, that doesn't mean that I don't look after my health, on the contrary. I pay attention to my health, to what I eat, what I experience. But I think we're luckier than others. (Man)

### ***Biographic Trajectories: Breakdown, Continuities, and Discontinuities***

Our objective was to understand how HIV-infection and HIV-controller status influenced the life trajectories of interviewees. Each interviewee not only talked about the dimensions of his/her life most affected by HIV infection, but also about unaffected dimensions.

Individual accounts of HIV diagnosis are the genesis of every PLHIV's story. Even after several years, the emotions aroused by the initial announcement of infection may still be very present. Accordingly, recounting

this experience may rekindle the shock of diagnosis or the fear of an early death. All these reactions constitute the first step of biographical disruption. The expression "the ground was falling out from under me" is a good illustration of this. Only one PLHIV declared that HIV diagnosis had had no impact on her:

So, I left his office, I was stammering, I think so anyway, I left, and the ground had just fallen out from under me. (Man)

How does HIV diagnosis affect a patient's life? Some HIV controllers try to keep continuity between their lives before and after diagnosis, by attempting to keep their daily lives unchanged. Others introduce radical changes into their lifestyle:

So I'm a girl who fights quite hard. I said to myself, "come on, I'm not going to let myself be beaten," I've got to get out of this and all that. And then like, you don't see it. You can't see the disease. For me, I didn't have any symptoms. I didn't have anything, so I said to myself "come on, I'm going to continue to fight." And I moved on. We do tests after making love, we use condoms because I don't want to infect him. (Woman)

Retrospectively, the life dimensions most affected by HIV were participants' intimate lives, sexual lives, professional lives, and also maternity for women.

After implementing adaptive strategies upon diagnosis, when they noticed that infection was not affecting them, the HIV controllers gradually realized that perhaps they were not going to die as quickly as they had thought. Most were not able to express how or when this happened. Some still did not exactly understand their "medical particularity." Trajectories differed according to the initial post-diagnosis experience and modifications to their lifestyle.

Accordingly, the non-appearance of the virus did not pose any problem for those who tried to continue life as normal. They ensured they did not contaminate their partner(s), regularly rechecked their serostatus, and hoped for a future without the disease. In this way, some HIV controllers explained that they no longer thought about HIV, that they no longer felt they were ill, that they no longer feared dying, and that they were less worried:

And gradually, like over time, I saw that I always had a low viral load and that I didn't have treatment. It's been 18 years now, so I feel well, like, things are good. I'm in good health and it doesn't worry me like at the beginning when I found out I was seropositive. (Woman)

The years go by, I always go for check-ups, I'm well, I live with it without having it in my mind like, after I go to the hospital they tell me that everything's fine. (Woman)

Conversely, for patients whose diagnosis brought about changes in their life trajectories, the non-appearance of symptoms after several years sometimes made things more complicated. For some, being ill had an important place in their identity. The certainty of an early death and of suffering serious symptoms prevented them from planning their future. Today, the lives of these same individuals are not always satisfying. Some realize that they will not fall ill, and accordingly that they must make new plans for their future. Indeed we can describe this as a second biographical disruption (professional and emotional change).

Others were still afraid of becoming ill. They preferred living from day to day, and were not able to plan their future. Their identity, and socio-professional and/or emotional positionings were all linked to the disease. Accordingly, in their opinion, their "sentence" was sometimes harsher than the certain early death announced years previously. It meant dealing with issues of "living with" the disease: living with the symptoms some PLHIV felt, living with the fear of falling ill, living with the impossibility of having full emotional and sexual relations, and living with the fear of being stigmatized:

You're afraid of everything that could happen so you're blocked on something and can't move forward, at least I can't move forward on this. And then, there's your age as well, I'm 51, so it's work, I find refuge in work. Work, work, work. No life outside of work. You can't see how it's possible to rebuild something, at least that's my situation. I don't see myself ever living with someone again, rebuilding something, because I think it'd be complicated. (Man)

### *Identity: Healthy/III*

The specific trajectories of each participant helped us understand in part how HIV controllers give sense to their situation and experience. A large portion of those interviewed did not consider themselves ill. This was explained by the absence of symptoms, not taking treatment, and also by a feeling of being in good physical health. For one of them, this feeling grew gradually, to the point where she found herself talking about AIDS using the past tense:

And then, like, my life with seropositivity, there isn't any problem. I don't consider myself to be a sick person because I'm not sick. I'm in great health. I live a healthy and balanced life. I live the life I want to live and nobody will ever be able to take that from me. No, I know that I won't die from AIDS. If I'm to die it'll be from old age, nothing else. (Man)

For another, accepting that he was ill took time:

I hid many things from myself. I spent a lot of time thinking I was becoming a disabled person. You need to say things clearly. It took me a long time to admit, even though my

brain works more or less, I had a lot of trouble sometimes even getting my carcass out of bed. (Male)

*Symptoms.* Several patients reported having symptoms which they associated with HIV infection, and which were present in varying degrees. Three of them spoke of moments of exhaustion which, in their opinion, were linked to their fight against the virus:

And then the fact that it stops you. And what's more, now, effectively physically, it stops me because I'm very tired, really, really exhausted constantly. (Man)

Three interviewees talked about skin spots or skin infections which recurred regularly but which did not impact everyday life, while more serious health events were often reported by those who considered themselves ill. It seems that it was the recurrence of symptoms and their severity which made sense for the individuals. "I've had infections which are certainly . . . well, skin things, things like that, but I've never had . . . I was always followed by Professor C. until he retired not long ago" (Woman).

The question of impaired mental quality of life was also indirectly mentioned by many interviewees. For some, it was one of the symptoms, or at least one of the consequences, of their infection. For those who talked about the issue, it had an influence on the lives:

For me it's not physical it's mental. Sometimes anxiety attacks, like I live 40 from the beach at C and like I stayed 3 or 4 days lying down at my home . . . It's depression, I don't feel well in my head, I don't feel like anything, it's a void. I mean we all have problems. Apart from that everything's fine. (Man)

*Care.* The relationship with care was different for each person interviewed. Some participants explained that they had periods of avoidance of follow-up or of hospitals. This helped them to distance themselves from the disease:

Apart from that, well, my life hasn't changed that much, my life is normal. There's no treatment so I don't really know what I can say. That's about it. [ . . . ] I've an appointment every 3 months but apart from that after the appointment I go back the following month for the results and after I go back again 3 months later. Three times a year, it's not very restrictive. If I had to come minimum 6 or 7 times a year it would be difficult but 3 times is alright. (Man)

*Feeling of social success.* Three interviewees underlined the importance of work and family, and their social development in these domains. These patients did not feel they were ill:

Like, and there you have it. I live well with it. I'm okay in my head. Frankly, I'm well, I don't know if that's going to

continue, for now I want to move on like a normal person. I'm well integrated into society I think. I've got a job, I get on well with my colleagues. Less well with others of course, you can't get on with everyone. [ . . . ] I've got a job which I like. (Woman)

Conversely, another interviewee who felt that he was ill talked about his lack of professional and social success.

*Social recognition.* A final element linked in varying degrees to the feeling of being ill or not regard the social recognition given to the status of PLHIV and/or HIV controllers. Accordingly, those who felt they were ill suffered from a self-perceived lack of recognition from doctors, their family, and their seropositive peers. Only three interviewees talked about this issue. These were the same three patients who declared they were homosexual and who seemed most involved either in the gay community or in organizations fighting against AIDS. One talked about his relationship with seropositive people who were not HIV controllers, explaining that sometimes it was uncomfortable for him to be in front of these people with whom he had shared the initial experience of disease but who had completely different experiences today. Although not explicitly mentioned, it seemed as if he felt guilty about the fact that he was not ill. He talked about the similarities between HIV controllers and other seropositive people, the possibility of being understood by the latter, the differences between both groups, and the distancing which PLHIV who are not HIV controllers create:

All the same, as regards the group that I was part of . . . we see each other, at least at the time we saw each other quite a lot and all that, it wasn't easy and it's still not easy either, because [these] people, they've got more difficult stuff, painful, long, tough medicalization and so on. "And you?" "Eh no" . . . But, there you have it, you see people who are hospitalized, you go to the hospital, and all that, all that. It really isn't simple you know, at the same time, it's not a status really . . . Like, it's really comfortable, and just as well. I have no wish to start getting something but in the end it's not always easy, being able to feel comfortable with that. (Man)

Another mentioned the lack of recognition of his seropositivity, as much by PLHIV on treatment, as seronegative people and doctors. He wanted to have people recognize the difficulty of his experience. He was faced with a situation where his status as an ill person was denied because he did not take any treatment, despite the fact that he considered himself to be ill. He completely identified with seropositive people but suffered greatly from the fact that they did not recognize him as one of their own. Consequently, he wanted the situation of HIV controllers in general, to have more media coverage:

And it's difficult with doctors. Even though HIV controllers have been officially assigned a name, when I speak to them about being tired they don't really listen to me, they're not interested because it doesn't show up in the blood tests . . . Now they say "perhaps you won't die of AIDS but you must take stuff to avoid a heart attack," that it's connected with HIV. Like, the best cardiologists tell me that I'm not HIV positive, but I am, it's really complicated to live with, to cope with all that. (Man)

## Discussion

The results presented here come from new data collected from HIV controllers, a population that until now has not been interviewed in any great depth about their experience with their unique situation and related paradoxes. Data analyses from the 14 interviewees show that HIV-controller discourse was organized around four primary categories related to their life from an historical and biographical perspective. The representational processes surrounding HIV in general, and an understanding of the causes of their situation, help HIV controllers to reduce uncertainty about their particular status and their future.

First, from an individual point of view, HIV controllers must cope with the difficult element of HIV-related social discourse. Before becoming aware of their HIV controllers status, they thought their future reality would have been that of a classic HIV-diagnosed individual. For those who still fear falling ill, telling themselves that living with HIV is much easier today, and that things will certainly improve in the future, is a means for them to reduce their uncertainty. For some interviewees, this HIV-related social discourse seemed quite removed from their personal experience, for others it was not. Classic seropositive patients have the same questionings. Since the advent of HAART in 1996, their conception of time has become closer to that of healthy people, thanks to the disease becoming chronic in nature. Uncertainty is being substituted with hope, thanks to "managing uncertainty" (Mendès-Leite & Banens, 2006). HIV controllers build this hope through their trust in medicine which, in their opinion, will one day eliminate HIV. In 1997, Pierret discussed such expectations in asymptomatic patients and suggested that while it is important to have an understanding of how experiences and representations influence identity building, it seems necessary to first revisit a more specific representational element: the concerns and beliefs of informants about their situation (Pierret, 1997).

The patients interviewed here explained their situation using a medical-based discourse (as opposed to a personal-based discourse for example). This enabled them to trust research so they could construct an optimistic representation of their future. Their trust in medicine helped them use their scientific knowledge to explain their

particular state. This process was also observed in patients interviewed by Pierret (1997) as a way of keeping hope.

In our study, patients had a good understanding of the scientific knowledge provided by doctors in consultations. They transformed this knowledge as best they could to make sense of their situation (Clémence & Green, 2006). Accordingly, the hypothesis of a stronger immune system explains other experiences. For some, genetic makeup was associated with good luck. Indeed, the question of luck came up regularly.

The experiences of HIV controllers in this study are similar to those which Pierret (2001) describes. In his study, Asymptomatic in Long Term (ALT) patients seeking an explanation for their situation also described luck, the necessity for a healthy lifestyle, and above all, physical and mental strength, elements which were also important in our study. The difference between both studies perhaps lies more specifically in the link with medicine, which was less present in Pierret's study. Certainly, medical research was not as advanced at that time.

Keeping one's character "innate" and not temporary was one way for HIV controllers to internalize control over their situation in our study.

In Pierret's (1997) study, patients interviewed just after infection adopted a healthy lifestyle, to have a feeling of control over their illness and to build hope. In our study, this lifestyle choice, also adopted by certain HIV controllers at the beginning of infection, may have provided them with an explanation as to why they did not have classic HIV symptoms. Moreover, a feeling of control over one's health, and more specifically over the disease, has a positive impact on individuals' quality of life (Préau et al., 2005) and physical well-being (Sirois, Davis, & Morgan, 2006). It also helps lower levels of depression (Newsom, Knapp, & Schulz, 1996). These facts help us understand better why patients use strategies that enable them to increase internal control. The belief in a healthy lifestyle and moral strength, which help maintain a good state of health, are factors encouraging a satisfactory quality of life for some of the patients interviewed.

Yet among those who felt they were ill, some did not have the possibility to implement strategies to improve well-being. In addition to difficult everyday symptoms (fatigue, health events, loneliness, depression), these patients believed they were not recognized and therefore felt they had very little support. The lack of "classic" symptoms associated with HIV infection, but mostly the fact that treatment was unnecessary, made their HIV infection "socially invisible" (Lonardi, 2007). Very often they felt they were not considered ill and therefore could not benefit from the social support they felt they had a right to as PLHIV. Our HIV controllers found disclosure difficult because, in their opinion, it aroused suspicion in doctors, family members, and friends about their honesty

and about whether they were really suffering. This constitutes a factor for social insertion breakdown.

Life trajectory, reactions upon diagnosis, and changes in daily life and in life choices are specific to the individual. Mendès-Leite already highlighted this problem of "redeploying one's temporality" in PLHIV when effective therapies first became available defining it as the "mourning of being in mourning" (i.e., mourning one's own future death), yet all the while facing incertitude (Mendès-Leite & Banens, 2006). And this mourning is even more difficult for patients who have seen too many people die around them.

To understand this process of mourning, it was necessary for interviewees to reexamine their priorities and clarify the difference between being ill and feeling ill. For most HIV controllers interviewed, however this divide was not always clear. Those who felt they were ill did not necessarily suffer as a consequence, whereas those who no longer thought about their serostatus still had moments of worry. In particular, older patients were afraid that as time passed, their aging body would lose resistance and no longer control the virus.

Conversely, in some cases, having HIV-controller status meant being able to forget the illness. One interviewee mentioned that the harshness of some HIV information campaigns reminded her of the seriousness of her disease, although she did not really think about it often. Pezeril highlights that campaigns in the fight against AIDS increasingly use arguments that stigmatize infected persons and underline the disease's problematic nature (Pezeril, 2011).

The different biographic trajectories from these 14 interviewees helped us shed some light on their self-identification and on their feeling of being in good health or not.

Social representations also enabled us to acquire a greater understanding of the lives of patients on the frontier of good health and illness. Today, whether a HIV controller feels ill or not, or feels he/she is in danger or not, depends on several factors. Some still have the sword of Damocles hanging over their heads, whereas others think about the future without worrying. Care provided to HIV controllers must be tailored to meet all these situations. The role of doctors is vital, as they legitimize the state of good health which some HIV controllers report. For those who feel they are ill, doctors have a more subtle role: They must provide support and recognize the disease, all the while encouraging in HIV controllers a feeling that they have control over their own situation. Pierret underlined that the destiny of seropositive people is individual yet closely linked to the group in general (Pierret, 1997). The fact that those HIV controllers who mentioned that they found it difficult to identify themselves in relation to PLHIV on treatment were all homosexuals, is not

insignificant, as their destiny was initially linked to that of many other gays infected in the 1980s and 1990s, but over time, their individual experience distanced them from that the rest of the group.

Second, from a social and contextual point of view, the present study brings elements of understanding about the construction of HIV controllers' social reality. Several of these elements help us understand why some HIV controllers feel they are ill whereas others feel that they are in good health. Indeed for each HIV controller, their experience of living with their particular situation partly depends on this feeling about their health. Two very important elements are symptoms (which are sometimes present) and the care provided. However, the most important element we found was related to their feeling of social success.

Finally, we can link this feeling about one's health with the individual's biographical trajectory. Pierret underlined that some patients trying to maintain normality as best as possible in their life did not change their life trajectory (Pierret, 2007). We found the same results for HIV controllers, where patients who expressed they felt they were ill were the very patients who had implemented a substantial change in their life trajectory after diagnosis. Accordingly, the feeling of being in good health or being ill would seem to be linked to changes which occur, or not, at the moment when seropositivity is announced.

Some study limitations have to be acknowledged. First, those patients who agreed to participate in the cohort may have had better follow-up and greater overall satisfaction with care than patients who did not agree to participate. This possible bias was certainly reduced by the specificity of French access to care, which unlike many other countries' national health care systems guarantees generalized, free-of-charge access to care for all HIV-infected patients. Consequently, patients included in our cohort are much more likely to represent the general French HIV-controller population. Second, this study was conducted using a qualitative approach, which did not aim to be representative of the population through the use of a large number of interviewees, but rather aimed to understand and comprehensively analyze the daily-life experience of interviewees and the meaning which they give to their special status by collecting high-quality data.

## Conclusion

Our study presents novel data about the daily life of HIV controllers, and highlights the specificity of living with HIV-controller status in comparison with "classic" HIV-infected people. On a theoretical level, our study shows that this particular medical situation generates a very specific experience which lies on the frontier between HIV-infected people and non-HIV-infected people. First, our

study shows that beliefs, representations, and behaviors of HIV controllers are largely influenced by initial experience as HIV-infected people, before being diagnosed as HIV controllers. After this diagnosis, beliefs changed to build an identity without a true sense of belonging to a group. In this context, HIV controllers found disclosure difficult because, in their opinion, it arouses suspicion in doctors, family members, and friends about their honesty and about whether they are really suffering. This constitutes a factor for social insertion breakdown. Second, these results underline the necessity to develop not only tailored follow-up for these patients, but also social representations theory, which is linked to daily life (Jodelet, 2006), and which provides crucial elements for future use by health professionals caring for HIV controllers.

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