Experiences of living with HIV, an analysis over time (1990-2000)

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Abstract: Qualitative data from three research projects carried out in France are used to analyze changes in the experiences of persons living with HIV during the ten-year period from 1990 to 2000. During this decade, 167 in-depth interviews were conducted with 118 HIV-positive people in 1990-1991, 1996-1997 and 1998-2000. A three-fold typology — "continuity with drawbacks", "discontinuity and reversal" and "withdrawn" — is proposed to account for the experiences of living with HIV in relation to changes over time and the discovery of new treatments in the spring of 1996.
Key words: typology of experiences, people living with HIV (PLWHs), highly active antiretroviral therapy (HAART), time, medicine, France.

Given that the history of HIV/AIDS has lasted for more than two decades, social scientists have had the possibility of analyzing in vivo the emergence of a new illness condition and the discovery of its first treatments. The experiences of persons living with HIV (henceforth PLWHs) have been used to study this exceptional situation. To this end, the interviews carried out in three separate research projects conducted in France between 1990 and 2000, have been analyzed anew. During the 1990s, social, political, medical and scientific changes deeply affected the lives of the HIV-positive. This article seeks to show how, during this decade, the experience of HIV-infection evolved under the combined effects of changes over time and in this structural context.

Methodology and context of the research

Three qualitative research projects conducted in 1990 (Carricaburu and Pierret 1995), 1996 (Pierret 2001) and 1998-2000 (Pierret 2004) can help us understand how people learned to live with HIV-infection at three distinct moments in the history of AIDS. In all, 118 HIV-positive persons were interviewed in depth. Since some persons were met three times between 1998 and 2000, 167 interviews were carried out, the average interview lasting over an hour. Doctors followed a similar protocol for screening volunteers from among their patients for each of the three studies. The table presents a profile of interviewees.

INSERT TABLE HERE

Each interview started with the same open-ended request: "I'd like you to tell me how you've lived since learning you were HIV-positive and how things have worked out in different areas of life." Interviewees brought up the topics they wanted to talk about with minimal intervention from the interviewer. All interviews were taped and transcribed. The excerpts presented herein bear indications of the date of the interview, as well as the person's age at that time, and the date when he/she was diagnosed with HIV. The analysis of this material focused on the question: how does someone live with uncertainty and a deadly illness?

The first set of interviews in 1990-1991 was carried out with 53 men who had been infected with HIV for at least two years (in French: séropositifs). On 31 March 1990, France reported 9.718 AIDS cases, 85% of them men; but the number of the HIV-positive was poorly estimated. The first antiretroviral, AZT, was prescribed for people with AIDS in 1987. The CD4

count was, till 1996, the major biological indicator for monitoring the shift from HIV-positive to AIDS. In the early 1990s, AIDS still meant an early death (Carricaburu and Pierret 1995).

By the time of the second qualitative study in 1996-1997, a group image of the HIV-positive and PWAs had gradually taken shape in the media and through campaigns by AIDS organizations. Doctors were now measuring the "viral load", the major indicator of the illness condition since the spring of 1996; and in March, the first protease inhibitors were being prescribed. Since 1993, it was known that the HIV-positive might not be sick eight years after infection. The 1996-1997 interviews involved 30 "long-term HIV nonprogressors", 24 men and 6 women, who were part of a biomedical research project (Pierret 2001). These interviewees had a high CD4 count (at least 600) but were not receiving treatment. They had been diagnosed with HIV at least eight years earlier.

The "treatment revolution" known as HAART (highly active antiretroviral therapy) reshaped the context for the third research project, carried out from January 1998 to July 2000 (Pierret 2004). The life expectancy of patients was rising; and the onset of AIDS postponed. Interviews were conducted with 35 HIV-positive persons drawn from a biomedical cohort (APROCO, AntiPROteases Cohort) formed as of May 1997 out of persons who had gone on HAART. The 27 men and 8 women interviewed as of January 1998 had just started HAART. Out of these 35 persons, 21 were interviewed three times: the first time when told they would go on the new medication, then during the eight and twentieth months of treatment. After the introduction of combination therapy, the current phrase "people living with HIV" (PLWH) would come into use. Till that time, the HIV-positive and PWAs were living in dread of AIDS and of dying.

A typology of experiences

The contents of all 167 interviews were analyzed by focusing on how these HIV-positive persons said they organized their lives and on how they formulated their accounts. Once imbued with these interviews by repeatedly reading and scrutinizing the transcriptions, we arranged the concerns expressed by theme so as to bring to light the characteristics that could serve as the basis for a typology.

The illness experience, i.e., the study of the effects of the onset of chronic illness on patients' lives (Bury 1982, 1991; Conrad 1987; Charmaz 2000) served as the analytical framework. Illness disrupts a patient's everyday activities because practical arrangements have to be made and, too, his/her sense of self and relationships with others have to be reworked. Research on the illness experience has mainly concentrated on connections between the patient's subjectivity, living conditions and cultural/educational resources (Lawton 2003) while overlooking structural factors in the medical, scientific and political contexts (Pierret 2003). In effect, the ways that social policy, the organization of health care, the state of medical knowledge, the media and activist organizations affect the illness experience have not been adequately studied. Two exceptions can be pointed out in the studies of how medical technology had an impact on patients' lives (Locker and Kaufert 1988) and how changes in hospital policy affected the type of patients admitted in English hospices (Lawton 1998). The introduction of HAART in 1996 was a structural factor that deeply affected lives at a time when the AIDS diagnosis still sounded like a death sentence. However the illness-experience approach turned out to be limited when analyzing how the passage of time and the aforementioned structural factors affected what interviewees meant when claiming to be "living a normal life", whether in 1990 or in 2000 (See Pierret 2006 for a full analysis).

Three types of experience of living with HIV—"continuity with drawbacks", "discontinuity and reversal" and "withdrawn" (from the French word *enfermement*) — were constructed out of these qualitative data by combining two aspects: the form of the interview (whether the account was chronological or not, whether or not interviewees admitted that changes had occurred in their lives, and how past, present and future were connected) and the themes spontaneously brought up and their meanings (work, control over the "secret", information management and relations with the medical establishment as well as personal relationships and activities). These themes represented both resources interviewees tapped and problems they had to solve in order to cope with their new condition. Not only did these three types prove useful for understanding time as a duration with effects on people's lives, they also took on meaning in relation to the objective conditions of interviewees' lives and to structural changes during the 1990s.

All three types of experience of living with HIV were observed during each research project, which corresponded to changes in the medical and scientific context. Despite minor

shifts, the types did not change significantly over the decade. They never overlapped, although the type best characterizing an individual's life might change depending on the circumstances and period. For example, the type "withdrawn" might best characterize someone whose socioeconomic status had declined or whose social bonds had been severed following a period when he/she had experienced life with HIV as a "continuity with drawbacks".

These types bore the deep imprints of the social institutions that shape identities in our society, in particular, work and the welfare state with its classification of beneficiaries and entitlements (Schnapper 1999). In fact, fewer than 20% among these 118 interviewees were economically inactive at the time of the initial interview. Nor can we understand illness without taking into account a third institution: medicine, which opens access to welfare by legitimating the patient's condition. A patient experiences illness in relation to his/her economic (in)activity and to medicine.

Continuity with drawbacks

One type of experience of living with HIV takes as a point of reference the period before the person learned he/she was HIV-positive. It was detected in 1990 with those who wanted to prove they were still alive despite the gloomy prospects as well as in 1998 with those who were going on HAART. This type represented more than half the interviewees (including 8 out of the 14 women) during the decade. All these persons were socially and occupationally integrated when they learned they had contracted the virus. After the diagnosis, they asked themselves, "How to go on living?"

Holding a job and keeping the "secret"

At the time of the interview, all persons experiencing their condition as "continuity with drawbacks" were still in the same line of work as at the time of diagnosis. They held relatively skilled jobs. Work was essential to their equilibrium and meant, above all, maintaining continuity with life prior to infection. In the words of a man (32 years old in 1990, diagnosed in 1987, infected through homosexual intercourse):

> "I have an occupation I like, it really interests me. I work from twelve to fourteen hours a day, and don't get more rest than I used to. I haven't taken a vacation for two years now [...] I went into business in prosthodontics five years ago, at the start with three partners, but I bought the others out. For the last year and a half, I've been working alone at the head of the company."

By the late 1990s, the virus was spreading to less well-off social groups. Although more PLWHs were then holding unskilled or harder jobs, persons of this first type still valued work: an occupation represented the very meaning and condition of a "normal life". Nor did HIV-infection turn out to be incompatible with the search for employment or with plans for switching jobs or even occupations. A man (41 years old in 1998, diagnosed in 1991, infected through heterosexual intercourse) declared:

> "I was a security guard in a hypermarket, and I was dismissed [...] I had a hard time but found work fairly fast, a job in a newspaper. But I was doing replacements, so I shuffled about from one short-term contract to the next, filling in for people on sick or pregnancy leave. And so there were months when I didn't work at all, times when I worked for a day or a week. It was pretty haphazard."

Work was seen as the only way toward recognition and integration. These interviewees set even greater store on the social utility of working insofar as they knew that AIDS, by cutting their relations with work, would sever social ties.

Controlling information about the diagnosis — knowing whom, when and how to tell — was the second main condition for living normally with HIV. The serostatus was usually a tightly kept secret, always so at the workplace. It might be shared with a few reliable persons. A stock room worker (44 years old in 1996, diagnosed in 1985, infected through homosexual intercourse) stated:

> "I told my parents in 1986, it took a while before I decided to. They reacted, well... it's not easy for parents [...] The right for someone not to know has to be preserved. If someone doesn't want to talk about it, it's important to respect that, intimacy is to be preserved, that's fundamental."

Keeping the diagnosis secret required constant vigilance, which was all the harder for someone known to be a hemophiliac, homosexual or intravenous drug-user. Repeated absences, the least visible symptoms or regular, daily medication risked disclosing what was to be

concealed. All these interviewees tried to conceal the taking of prescription medicine, like this fireman (36 years old in 1998, diagnosed in 1988, infected through homosexual intercourse):

> "Tritherapy was a bother at work because I might start at 5 a.m. or in the afternoon, and I put in night shifts. It's a problem, since the medication has to be taken at about twelve hour intervals. There are times when I take it at 9 p.m., then usually at 5 a.m. I often take it to work and put it in the fridge. My colleagues don't know, and I don't want to tell them. So there's teasing, 'What is it?' I don't say anything. I tell a fib. Things settle down."

The reason given for not telling was the fear of being pitied, rejected or misunderstood. But above all, the "secret" had to be kept lest others change their way of looking at the person, as Weitz (1990) was among the first to point out.

Besides holding a job and keeping the "secret", the two underpinnings of a normal life, other themes were brought up. In 1990, when medication did little to halt AIDS, it was very important to examine the body for "signs". Once HAART became available, paying attention to the body took on another meaning. The medication had undesirable — in some cases serious — side effects, such as tiredness or diarrhea. It was not always easy to tell the difference between these effects and the onset of AIDS.

Insurmountable drawbacks

Even though continuity with life prior to contracting HIV could be maintained despite drawbacks, if arrangements were made in social activities and at the workplace, there was no greater challenge than the effort to continue leading a normal sexual life. The risk of transmitting the virus deeply altered the emotional and sexual lives of all 118 interviewees. Some were living alone; others, with someone with the same or a different serostatus. Couples had formed or broken up since the diagnosis. The sexual transmission of HIV was an objective restriction for all interviewees but a literal constraint for those who were experiencing life with HIV as a continuity despite drawbacks.

The men interviewed in 1990 always broached this sensitive topic by referring to the period prior to infection. After infection, sex had to be safe, and the fear of spreading the virus to others was ever present. The medical imperative of safe(r) sex was a norm, despite qualms and

strong misgivings about condoms. In fact, homosexuals distinguished between "condoms" and "protection", the latter involving a strategy of risk reduction and "negotiated sex" (Pollak & Schiltz 1993; Kippax et al. 1993; Keogh, Beardsel & Sigma 1997; Delor 2000). A journalist (35 years old in 1990, diagnosed in 1985, infected through homosexual intercourse) said:

> "I pay close attention. I've cut down on the number of partners, I don't go to certain places any more, but I don't use condoms. I feel that a relation isn't just penetration, there's everything else that's sensual."

By 1996, interviewees — persons living for more than eight years with HIV — admitted that time was taking its toll, since they were having trouble practicing safer sex and leading a normal sexual life. These "long-term nonprogressors" were preoccupied with their emotional reactions to this situation. Over the years, their "good" test results had led them to "forget" the infection during everyday activities; but sexual intercourse still reminded them of the virus and rekindled anxiety. In the words of a doctor (42 years old in 1997, diagnosed in 1985, infected through transfusion in 1983):

> "For two years before learning the diagnosis, we didn't take any special precautions. My husband took the test, he was never infected. [...] The idea of a sexual relation is systematically associated with the fear of spreading the virus. [...] It's not a moment of bliss for me."

By 1998, the phrase "safe(r) sex" was seldom heard, even though using condoms had become widespread. The major concern was no longer with emotional responses and sexual practices but, instead, with holding down a job while complying with a grueling regimen.

There was no effective treatment for HIV-infection before AZT in 1987. This drug, originally used to treat cancer, was prescribed at the onset of AIDS; but many people and organizations had doubts about it (Epstein 1996). Men in the first research project knew that AZT, though not a cure, offered the only hope of "stabilization". They were forced to "make do" even as they watched for signs of the trouble to come, and would wonder whether they came from taking AZT or from the advancing disease.

Not all the interviewees diagnosed before 1990 were receiving regular medical care. Some of them preferred "doing as if", and had irregular medical appointments at best. Once HAART was prescribed in 1996, the HIV-positive had to learn to live not only with the virus but also with a treatment. Their situation was beginning to resemble that of people living, thanks to medicine,

with other chronic illnesses. Over the months, they had to learn to "incorporate" the treatment in everyday activities: to live with it despite changing prescriptions, doses or preparations and, above all, despite any concomitant "inconveniences". Once the new treatments became a mainstay, these persons — now living with HIV thanks to the new therapy — had to adapt the medical regimen to their lives.

Time, change and normality

The meaning of "continuity with drawbacks" shifted when HAART was introduced. Previously, the HIV-positive were actively and fully responsible for "living normally" despite the pending death verdict. In 1996, they started sharing the responsibility for this continuity with health-care professionals. The meaning of "uncertainty" also shifted to refer to life on a daily regimen with unknown long-term effects. However interviewees of this first type tried to keep the medical model of the compliant patient and its values at a distance, to limit it to appointments and the treatment, since they wanted to avoid altering the image they had of themselves as well as the image they projected toward others.

The intention to keep on living "like before" meant that everything was fine, "normal". Continuity with the past became a standard for living with the present uncertainty. Despite the intent to "do as if" and continue as long as possible "like before", the meaning of "before" was successively adjusted, especially following medical breakthroughs. For instance, the referent shifted from "before diagnosis" to "before doctoring" or "before taking part in the protocol" and then to "before going on treatment". The relation to time was paradoxical, an aspect that other studies (Davies 1997; Ezzy 2000) have failed to point out. On the one hand, "before" meant the continuity of a normal life while, on the other hand, plans (such as buying a house or setting up a business) were pursued without consideration for the long term.

In 1990, when medicine lacked effective means of intervention, appointments with doctors might be irregular or even inexistent. For individuals to continue living as long as possible as they did prior to diagnosis, they had to be able to tap resources for staving off AIDS. Time was one resource for building up the hope necessary for living, at a time when a biological category (having an HIV-positive blood test) was turning into a social one (being HIV-positive). By 1996, the so-called long-term nonprogressors were leading their lives as a continuation of an

ever receding past. The medical establishment declared them to be an exceptional category owing to the duration of their illness condition. After 1996, with the instroduction of combination therapy, people were learning how to live with the uncertainty of HIV-infection while trying to comply with a new treatment. Time seemed suspended with reference both to an ever receding past and to a self-image that remained identical for oneself and for others.

This first type, which covers the majority of interviewees, might be applicable to any long-term illness receiving medical treatment: "You live with it". While leading a life that others considered to be normal, these interviewees strongly wanted to present themselves as persons living with HIV instead of as persons with AIDS, as being on treatment instead of being sick.

Discontinuity and reversal

The experience of "discontinuity and reversal" emerged out of the questions that loomed after the diagnosis, inevitable questions about the meaning of a now uncertain life that had to be "normal". The point of reference was life with the adjustments and changes since infection. Everything since then was valued as a reason to go on living or fighting. Contracting HIV triggered an awareness that ended up reversing the ordeal's meaning.

Representing approximately a third of interviewees during the decade, this second type corresponded to three different situations: the youngest participants, who entered adulthood with HIV-infection ; as well as people who changed their way of living a few years after the diagnosis ; and those who, despite chaotic phases of instability prior to the diagnosis, developed a questioning attitude afterwards. In all three cases, a rather long process with ups and downs eventually led to a new choice that marked a break with the previous life. When life had been hard or unstable, the reversal might be long coming and might itself be reversible, as was observed between 1998 and 2000. Only one woman fitted under this type. Could this be due to the small number of women interviewed (13% in all) or, instead, to the difficulties that women had reversing the meaning of their experience of a long-term illness that was associated with men, drug-use or, especially for women, sexual promiscuity?

This questioning attitude led interviewees of this second type to wonder what they should do to cope with uncertainty. They did not just try to hide marks of stigma or reinterpret them so as to reject the discredit borne by HIV/AIDS. They reversed the meaning of the illness experience

so as to transform the time left to live. Other sociological studies have also referred to this process of reversal. Herzlich (1973:114) defined a category, "illness as a liberator", when illness, once legitimated by medicine, is experienced as a time of liberation from the pressures of everyday life and work. Ville (2005) has drawn attention to patients who fit their disability into their biography so as to change their way of life. Schnapper's (1999) typology of the sense of identity and experiences of unemployed wage-earners resembles the one proposed herein, except that the experiences of living with HIV take on meaning in relation not just to a socioeconomic status or the welfare system but also to questions involving the body and life itself.

Resources for putting up a struggle

The interviewees experiencing "discontinuity and reversal" were hyperactive. They worked long hours, took examinations, and some of them even switched jobs or pursued several activities at once, like this businessman (35 years old in 1996, diagnosed in 1985, infected through homosexual intercourse):

> "What hurts most is to see friends around you die, and the close friends whose CD4 count goes crazy and who go on treatment. Then, a time came when I realized that being HIV-positive, given the shape I'm in, might be a chance. I lost a little sleep, but I made up for it with a thousand other things. I got a lot to do. I was already really active. Ultimately I'd have never had this overdose of energy — I think but I might be wrong — if I hadn't caught this disease."

Some of these interviewees chose to take a less engrossing job or reduce the time spent working in order to improve their quality of life and free time for other pursuits, in particular the fight against AIDS.

More than 20% of interviewees in this second type had not yet, when diagnosed, started a career or social life. Unable to fall back on an existing occupation like those who experienced "continuity with drawbacks", they had to make career plans. Those who, before (and, in some cases, after) diagnosis, were poorly integrated in society had trouble participating in the labor force. They switched from one "small" job to the next, back and forth between joblessness and temporary stints of employment until — realizing (often for reasons unrelated to their infection) that work was the only way toward social integration — they settled down into a steady job. Such

was the case of this man (41 years old in 1996, diagnosed in 1985, infected through intravenous drug-use):

> "I really lived an unconventional life till 35… traveling, sailing, freelance work now and then for newspapers. I always went for the going price but never really involved, committed, myself for the long run. […] I moved to the country, adjusted my work, I'm doing translations, writing short stories. I'm thrifty."

Persons of the type "discontinuity and reversal" handled the secrecy surrounding HIV in ways ranging from almost full disclosure to relative silence. Over the decade, few changes were observed in the frequency of the stances adopted. A male nurse (33 years old in 1997, diagnosed in 1984, infected through homosexual intercourse) declared:

> "After thirteen years, I told myself that I was right in not talking about it. That spared my family thirteen years of anxiety. But when I meet someone (sexually), I systematically choose to talk about it."

Lifting the "secret" might fit into a strategy for discovering, or rediscovering, a new meaning of life; and thus enter into the process of reversal whereby living would become a value, even an example. For instance, activists in organizations disclosed their "secret" in nearly all spheres of activity.

Although the same insurmountable drawback kept these interviewees, like all the others, from leading a normal sexual life, it did not hamper the process of reversing the meaning of the illness experience. Since many persons of this second type had started their sexual life with HIV, they did not refer to a relatively idealized past. Most of them practiced safe(r) sex, and some had even changed companions.

Relations with the medical establishment did not have the same meaning as in "continuity with drawbacks". These interviewees mainly valued medicine as a growing stock of scientific knowledge, even in 1990 when prospects were still grim. All persons of this second type had high expectations of science. They — in particular the activists — wove close ties with doctors and used them rather than the media as a source of information.

AIDS was certainly present in these interviewees' private lives; it or drug abuse had usually decimated their circle of friends. It was also present in the public lives of those who were activists. Contrary to what was said in medical circles or reported in the media, only a few interviewees reversed the meaning of their illness experience once HAART was introduced.

Time to fight, time to change

What characterizes "discontinuity and reversal" is the importance of finding the strength to live and put up a fight. Since the diagnosis, this struggle ranged from a personal quest or a job to a collective combat, such as the campaign against AIDS. This second type brings to mind the "quest narratives" and "living with a philosophy of the present" described by Davies (1997), but the short-term planning or religious beliefs characteristic of Ezzy's "polyphonic narratives" (2000:613) were not observed.

People of this second type coped with uncertainty through their occupational commitments, their confidence in medicine and their strong involvement in personal or group activities. The time left to live, though uncertain, was filled with "things to do", with the quest for self-fulfillment or the pursuit of plans. Since the present was to be occupied and turned into a time for fighting and advancing the cause, every event "made sense" in the person's life and plans. Time was discontinuous. This discontinuity both gave rise to, and arose out of, the reversal of the meaning of the illness experience.

Nowadays, available treatments have sped up the return to a "normal" life. Should this process be interpreted in the light of the normalizing role played by medicine since the 1960s, as advances in diagnosis and therapy have enabled the chronically ill to live with their condition? Consequently, will there be fewer persons who experience HIV-infection as "discontinuity and reversal"?

The withdrawn

For this third type of illness experience, the diagnosis of HIV-infection was but one more stroke of bad luck in a chaotic, unstable life without social or occupational moorings. Given accumulated hardships, these solitary persons had a sense of fatality that justified passivity, since it was all the harder to find meaning now that death was near. Feeling useless and idle, they depended on a few close persons, social workers or health-care professionals.

About one-fifth of the 118 interviewees were of the withdrawn type. This type included young, untrained or jobless, homosexuals who were struggling with their sexual identity, homosexuals 55 years old or older who were living alone, and men as well as women infected through heterosexual intercourse or intravenous drug-use. These profiles were evenly represented in this third type. Here we find the socially and economically underprivileged who lacked resources to fall back on or persons who, after a shifting life of turmoil, had managed to find an equilibrium that HIV-infection would upset. Although most of these interviewees lacked training or skills and held insecure low-level jobs in the service sector, they had not lived in utter poverty while young. The sudden intrusion of the virus destabilized already fragile lives; but it might, after HAART, keep them from sliding into deep poverty since it served as the grounds for recognizing them as patients.

Hardships and misfortunes

Despite wide differences in age and background, all the interviewees of this third type said their lives were meaningless. They all "put up with" their condition. Regardless of their age, they often described life before infection as an insurmountable "handicap". Contracting HIV signaled but one more point of no return. For instance, this carpenter (42 years old in 1991, diagnosed in 1989, infected through heterosexual intercourse) was now afraid of cutting himself:

> "My life is a drag, I'm alone, I always traveled a lot, traveled for work. You might say I'm a misfit, I never paid taxes. A stable job isn't a possibility for me."

Learning that they were infected plunged them into a void without resources for coping. It marked an irreversible breaking point in a life that was yielding to accumulated difficulties.

All these interviewees passively internalized their fate, even more so when their social and occupational integration was fragile, for example this woman (35 years old in 1998, diagnosed in 1987, infected through intravenous drug-use), who was living on welfare, stated:

> "My life was already chaotic because of a motorcycle accident at the age of seventeen. I didn't adjust, I haven't managed to get the upper hand. I always just sank. [...] I've not built anything, not done anything. Nothing advances in my life."

Despite decisive support from a few close persons, these interviewees gradually retreated into silence and cut off contacts, a withdrawal often resulting in a return to addiction.

Those living alone faced a major question but were unable to answer it: when and how to tell a sexual partner they were HIV-positive? The younger homosexual men managed to become sexually active once again. Systematically practicing safer sex with condoms, they sometimes told partners right away about their serostatus, but then complained about a lack of affection and warmth (Schiltz & Sandfort 2000). The older homosexual men, as well as the heterosexual women and men who were living alone, all suffered from solitude and emotional instability.

For the interviewees who had managed to restore a balance by moving or going to work, HIV reminded them of a past that they thought they had left behind. They wanted to keep the infection secret because of a sense of shame related to this stigmatized illness and to their past as a dropout or misfit. Women and the persons infected through blood products voiced their fear of being "contagious" and dangerous. According to an office worker (39 years old in 1996, infected by her hemophilic husband and diagnosed in 1985):

> "Four years after my husband died, I met a man, but I had a sexual block. And if I met another man, it would be impossible to confess my situation to him."

Might this "contaminated" blood not have reinforced shame about the body (Crawford, Lawless & Kippax 1997; ANRS 1999)?

However, not all these interviewees bothered with keeping the "secret". Secrecy might be lifted depending on the circumstances, for instance when asking for assistance.

A blurred sense of time, save for professional help

The interviewees corresponding to this third type of experience mixed up present events with events before and after the diagnosis. It is difficult to identify the period when the events in their accounts actually occurred. This approximate chronology blurred milestones in a life-story marked with ruptures and misfortunes. These persons were victims of their former life: a hard one marked by an unhappy childhood, accident or drug abuse. This type reminds us of what Ezzy (2000:611) has called "linear chaos narratives", which express "depression, anger, isolation and social dislocation", or what Davies (1997) has described as an "empty present".

For the withdrawn, a "normal life" did not mean putting up a fight but, instead, being a victim dependent on welfare benefits and support from a few close persons, health-care professionals or social workers. Few resources could be tapped to fight back and foster the hope

for a better life. Bonds, if not already broken, usually came undone as the individual became withdrawn. However this fatality and passivity did not keep these persons from actively seeking help from professionals, who became the crutches for sustaining a life without plans or attachments. Professionals were, at times and with varying degrees of success, able to help them set goals, or at least a schedule with regular appointments.

Medicine changed the meaning of this situation following the diagnosis, either by providing counseling (in 1990 when other means of intervention were lacking) or by providing treatment (once HAART was introduced) and thus recognizing the person as a patient. This assigned status of "patient" became indispensable to the livelihood of these withdrawn persons, since it opened access to welfare benefits. Furthermore, it was subject to less stigmatisation than the labels of alcoholic, drug addict or jobless. Of the three types of experience, this is the only one that took on a different meaning after the therapeutic revolution in 1996. Going on treatment forced these interviewees to see their existence, which they perceived as meaningless, as a life with medicine. To oneself and others, it meant being ill, being a patient entitled to care and services. Only the status of patient, granted by the medical establishment, could fill the void of a lonely, solitary life. To live "normally" thus came to mean leading the life of a socially recognized and assisted patient.

Conclusion

The three types of experience of living with HIV described in this article help us understand what the 118 interviewees had in mind when they talked about a "normal life". This typology has proven useful in linking changes in experiences to the context during three different periods and in reckoning with time as a duration and not just as a moment or phase, as in the studies by Davies (1997) and Ezzy (2000). Even though, in the spring of 1996, doctors, AIDS organizations and the mass media presented HAART as a turning point in the epidemic, persons had already been living with HIV-infection for years beforehand. A new therapy did not suffice to restore a "normal" life whenever disaffiliation or a lack of integration characterized the person's situation prior to diagnosis. Of course, many interviewees did experience a change — but not a radical one — as new drugs came out during the 1990s.

Medicine's role during this decade was not just limited to therapy however. In 1990, given its limited means of action, the medical establishment mainly performed the tasks of surveillance and counseling. Health-care professionals were appreciated for their human qualities. With the development of clinical trials and the invention of new drugs, medicine came to be valued mainly as a stock of scientific knowledge. Thanks to HAART, it reclaimed its therapeutic powers: the new treatment might not cure, but it did help beneficiaries live longer. Besides prescribing treatment, medicine also played a role of socialization and normalization. Under favorable conditions, some persons could return to the world of work and be socially integrated, while the precarious obtained the status of patient, which granted them rights and a place in society.

As of 1994 in France, the HIV-positive and PWAs were, after medical approval, able to obtain disability benefits. An Act of 2 February 2005 has modified the amount of these benefits as well as eligibility requirements. Will the HIV-positive still be covered, in particular new cases among immigrants? In recent years, the makeup of the population infected with HIV has changed: more than 30% of new infections involve persons from sub-Saharan Africa or the Caribbean.

However this key position of medicine as an institution in our society does not imply that the ill are reduced to the patient's role. Illness is not a phase of life as in acute illness, nor even life itself as in chronic illness. Instead, it is a state or condition that people limit to the time spent relying on medicine and, above all, that many try to keep at bay.

Does this typology hold for other serious, long-term illness conditions with which people live without feeling sick? In fact, more people are living normally thanks to regular medical supervision but without considering themselves to be sick. If, in the coming years, developed countries do not roll back the welfare state, medicine — owing to its authority for recognizing the illness state and thus opening eligibility for benefits — will still provide visibility and a status to the individuals who, living with such illness conditions, want to be recognized as whole persons and full-fledged citizens.

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Table

Characteristics of the 118 persons at the time of the interview					
	Three research projects conducted in France:	1990-1991	1996-1997	1998-2000	Total
Transmission via	Homosexual intercourse	24	16	13	53
	Heterosexual intercourse	9	3	12	24
	Blood products	20	6	1	27
	Intravenous drug-use	0	5	9	14
Gender	Men	53	24	27	104
	Women	0	6	8	14
Residence	Paris and suburbs	52	21	2	75
	Elsewhere	1	9	33	43
Occupational status	Active	51	26	23	100
	Inactive	2	4	12	18
Living	Alone	23	16	18	57
	With someone who was not HIV-positive	23	12	9	44
	With someone who was HIV-positive	7	2	8	17
TOTAL		53	30	35	118
Age	Average	36.3	39.9	36	
	< 25	4	0	2	6
	25-40	36	16	25	77
	> 40	13	14	8	35
Knew that they were infected for		4 years	9.5 years	6.3 years	
Out of these 118 persons, 76% had learned before 1990 that they were HIV-positive; 12% between 1991 and 1995; and 12%, after 1996. At the time of the interview, 46 persons were being treated, 3 were in a French-British clinical trial (Concorde), and 69 had never received treatment.					