

# Interviews and biographical time: the case of long-term HIV nonprogressors

Janine Pierret

*Centre de Recherche Médecine, Sciences, Santé et Société,  
CNRS/INSERM/ÉHÉSS, Paris*

---

**Abstract** In 1996-1997, I interviewed 30 men and women who, though infected with HIV nearly 10 years earlier, were still not sick and were not receiving treatment. The empirical data drawn from these interviews are used to show how the conditions and context of this research affected the stances adopted by interviewees and led them to centre their comments on their experience of time. The analysis of these data focused on the form of the interview and the conception of time. A typology is proposed of how time was constructed during interviews.

---

**Keywords:** AIDS, HIV-infection, long-term nonprogressors, qualitative sociology, uncertainty, typology of time construction, France.

## Introduction

As part of a research programme on everyday life with HIV, a programme that started in 1990 with a survey of HIV-positive men infected through homosexual relations or medical products used to treat haemophilia (Carriacaburu and Pierret 1992), I conducted, in 1996-1997, in-depth interviews with 30 long-term HIV-positive nonprogressors. My intention was to understand and analyse how a sense of time came into play in the long-term situation of life with HIV. The reconstruction of the past since they had become infected with the virus turned out, quite unexpectedly, to lie at the centre of this more recent set of interviews. This led me to work out a typology of the time spent living in uncertainty.

The 1990 interviews showed the importance of seropositivity as a precise moment that was not yet, for these men, a period of illness. In the early 1990s, medical science had few efficacious treatments for HIV-infection. These men used the interview situation as an opportunity to talk about the

time before they had been infected and to rework that part of their biographies (Pierret 1994). In other words, their past before the infection served to give meaning to life with the virus and to reconstruct a biography around certain aspects of their sense of identity from before the infection. As an explanation of this process, I used the notion of 'biographical reinforcement' to refer to the emphasis that interviewees gave to certain aspects of their sense of identity *before* infection (Carricaburu and Pierret 1995, Pierret 1997). This notion shed light on the relation between the interviewee's current situation and his reconstruction of the past as an individual and as a group member. For these men, HIV had not just infected them individually. It had attacked a generation, their own, the one to which they referred and with which they shared a history, the history of developments during the 1980s either in medical treatments for haemophilia or in a homosexual lifestyle. As this research showed, a biological category (having an HIV-positive blood test) tended to become a social category (being HIV-positive) and to serve as a temporal resource in the fight against the onset of illness and in the effort to build up hope (Pierret 1996).

The analysis of the set of interviews conducted six years later with another population brought to light a different situation (Pierret 1998). Instead of being centred on the biographical reinforcement of aspects of interviewees' identities from before the infection, these 1996–1997 interviews turned on both the exceptional nature of their situation and the long period of uncertainty running from the moment the person had learned he/she was HIV-positive up until the time of the interview. This was an unexpected finding. These differences between the 1990 and 1996 interviews in the meaning given to time can be related to two factors: on the one hand, the medical and scientific breakthrough in the spring of 1996 when new treatments were introduced; and, on the other, the context of this sociological survey, which interviewees tended to perceive as part of a major medical research project. Before presenting these results in more detail however, I shall comment briefly on the ways that the sociology of illness has worked out the notions of 'biography' and 'identity'.

### **Theoretical background**

Serious illness is a trying time for individuals, an ordeal that is interpreted socially and entails political interventions (Augé 1984). When such an illness breaks out in a person's life, it creates a Before-and-After dividing line, and raises questions about what had, till then, been taken for granted. This situation has been described as 'critical' by Bury (1982), who borrowed Giddens' term (1979), or 'limit' by Aïach *et al.* (1989). Regardless of the terminology, an event is described that upsets the habitual world and overturns ordinary frames of reference. To live, perhaps several years, with the illness, persons tap various resources so as to rearrange living conditions

and adjust to the new situation by redefining their relations with others and their self-image. All this has consequences for the person's biography and identity, all the more so in that, unlike other significant events, such an illness implies reference to a time limit related to the certainty of dying but the uncertainty of when death will occur.

Two different perspectives can be identified in the way studies in the sociology of illness deal with biographical accounts and identities. The one has focused on how identities are reconstructed following the irruption of serious illness, a catastrophic event, in persons' lives. The other has focused on how the patient's narrative of the event during interviews is a means of working out an identity. Both these perspectives have mainly developed out of biographical interviews with patients – interviews that have been analysed either along biographical dimensions or in terms of a narrative process. Since Strauss and Glaser (1975), research in line with the first perspective has concentrated on the patient's viewpoint and analysed how serious illness affects the patient's organisation of life, 'biographical work' and sense of self (Bury 1982, 1991, Schneider and Conrad 1983, Charmaz 1983, 1987, Corbin and Strauss 1987, 1988, Gerhard 1990). Although such an illness is unique for the individual, and takes on meaning in his life-story through his response to the questions 'Why me? Why now?', it is also interpreted with reference to norms and social values (Herzlich 1969, Augé 1984, Bury 1991). The second, more recent, perspective has focused on the meaning of the very act of conducting interviews with patients (Williams 1984). The interview situation has thus been analysed as a spatiotemporal setting that leads interviewees to organise their narratives. To this end, they use their memory coherently to arrange past experiences and to assert the continuity in their identity: 'The process of narrativity achieves the unity and uniqueness of the self' (Polkinghorne 1988: 186). Several studies of illness narratives have tried to show how patients, by talking about their illness, try to give meaning to their life-stories (Kleinman 1988). Through these narratives, patients fit their symptoms and the effects of illness into a new reality, which, as it becomes their illness reality, helps them to understand their experiences and to settle problems (Frank 1995). Among the studies of this sort conducted during the previous decade, Hyden (1997) has distinguished three types of relations between illness and narration: illness *as* narrative, narrative *about* illness, and narrative *as* illness. My research since 1990 has developed at the meeting point of these two perspectives. In this paper, I focus on illness as narrative: how do patients express and formulate their suffering?

### **The context and conditions of the research**

By the spring of 1996, the social, medical and scientific context of AIDS was changing radically. There were more effective ways of treating the syndrome and of following up HIV-positive people. My sociological study was carried

out in association with a medical research project, launched by three doctors at the French National AIDS Research Agency (ANRS) in 1994. This project intended to follow up a cohort of long-term asymptomatic HIV-positive persons till 2000 [henceforth the LTA cohort]. When recruited, all these long-term nonprogressors (with  $CD4 > 600$ ) had been infected for at least eight years, but none of them was actually sick or following a treatment. The project aims to study the cohort's biological, immunological and genetic characteristics so as to identify the factors explaining why its members have not developed full-blown AIDS. It is worth mentioning that this cohort is not part of a clinical trial. Its members do not draw any direct benefit from participating in the project, except for an annual blood test. By 29 April 1997, 75 persons had been selected for the LTA cohort.

### *Methodology*

The sociological study associated with this medical project has focused on the experience of living for a long time with HIV and on the arrangements made, as time goes by, in everyday life. Out of the 52 persons contacted when they reported for the yearly blood test, 30 (58 per cent) were willing to take part in the sociological study. Since initial contacts with all members of the cohort with a view to recruiting them for the sociological study always passed through doctors, I could not learn the reasons that had led some persons to refuse to be interviewed.

Interviews took place between October 1996 and October 1997, a period when protease inhibitors were starting to be widely prescribed. Semi-structured interviews (on average 90 minutes long) about the interviewee's 'illness event' were taped and then fully transcribed. The directions given at the start of each interview – "I'd like you to tell me how you've lived since learning you were HIV-positive and whether your reactions have changed over time" – were broad enough so that the person could freely bring up various topics and talk about his past. Emphasis was placed both on what had happened when these long-term nonprogressors learned they were HIV-positive more than eight years earlier and on what had occurred in the meantime.

### *The interviewees*

These 30 interviewees had, on average, learned that they were infected 9.5 years before the interview. Their average age was 39.9. Since they had not been recruited on the basis of social or demographic criteria, the group was quite diverse, as Table 1 shows. Eighteen of them had at least a high school diploma, and 26 were in paid employment. Their general characteristics, incidentally, do not differ significantly from those of the 22 others who refused to be interviewed. By comparison, the persons I had interviewed six years earlier had all been men, on average 36.3 years old and HIV-positive for four years.

Table 1 *Characteristics and means of HIV-transmission*

<i>Characteristics of the 30 interviewees</i>	<i>Means of HIV-transmission</i>				
	<i>Homosexual relations</i>	<i>Intravenous drug-use</i>	<i>Blood products</i>	<i>Heterosexual relations</i>	<i>Total</i>
Total	16	5	6	3	30
Sex:					
Men	16	3	5	0	24
Women	0	2	1	3	6
<i>Place of residence at the time of the interview:</i>					
Paris	10	0	1	0	11
Parisian suburbs	6	0	3	1	10
Provinces	0	5	2	2	9
<i>Living arrangements at the time of the interview:</i>					
in a couple	6	3	4	1	14
alone	10	2	2	2	16
<i>Age at the time of the interview:</i>					
<35 years old	5	3	3	1	12
36–45	7	2	2	2	13
>46	4	0	1	0	5
<i>Age when they learned they were HIV-positive:</i>					
<20 years old	2	1	3	0	6
21–29	4	3	1	3	11
30–39	6	1	1	0	8
>40	4	0	1	0	5

*The analysis of the interviews*

I give the results of the qualitative analysis of these semistructured interviews from two angles. One has to do with how interviewees understood the time of the interview itself: what meaning did they give to the opportunity to talk in the context of a research project? The other focuses on how they told their stories about the years spent living with HIV. This twofold approach enabled me to propose a typology of time and uncertainty. This was of analysing the contents developed as I repeatedly listened to the tapes and read the transcriptions. Thus imbued with these interviews, I slowly detected

the preoccupations of these persons and, too, their ways of talking about the past. Owing to the conditions and context (in particular the new therapy), I was led to pay as much attention to the formulation of the contents as to the contents themselves. During the phase of analysis, I came to reformulate the question that this research was initially designed to answer: how, given the aforementioned interview situation and context, do people talk about a life characterised by uncertainty?

### **At the time of the interview . . .**

Contacted at the time of their yearly blood test as part of the LTA cohort, most interviewees thought the sociological study was incorporated in the medical project. For them, the interview was a full part of a project for understanding why, as long-term nonprogressors, they had not developed full-blown AIDS. For most of them, it provided an opportunity for thinking about their past in an effort to find an explanation for the present. This reflective attitude led a few of them to volunteer to become more involved in research. One man, for instance, wanted to lend us his diary; and another, to donate spinal cord marrow for medical purposes. This wanting to co-operate closely with doctors ensues from the very existence of a research project on the exceptional situation of what used to be called 'long-time survivors' (on this sort of doctor-patient relationship, see Fox 1959).

Just as the medical and biological sciences were looking for the factors in their bodies and blood that explained why they had not come down with full-blown AIDS, interviewees were looking for an explanation in their lives. That is what they wanted to express during the interview. When talking about the years of life spent with HIV, they adopted the stance of doing their own research by trying to answer the question 'Why have I not fallen sick?'

### *Explaining the inexplicable*

At the start, each interviewee focused on how and when he/she had learned they were HIV-positive. The breach opened in their lives by the announcement of their serostatus had signalled the start of a period marked by uncertainty and death. Ringing out like a knell, this catastrophic event had split life into a Before and an After.

The interview situation forced participants to look back on the past, but this past was nearly always the time since they had been infected and learned they were HIV-positive. The problem was to explain why death had not come as predicted. It was as if recruitment into the LTA-cohort, as part of a research project for studying why they had lived so long, had blotted out the feeling of doom that had hovered over the past 10 years; as if these persons were now reassured that they had a future. In other words, recruitment was part of a 'sanction process whereby another – person or institution: a specific "other" dependent on the concerned event – renders a verdict

about the event's "true" nature' (Leclerc-Olive 1998: 108). By endowing the past years with an interpretation, the LTA project enhanced the end point and rendered a verdict that the situation of these persons was, indeed, exceptional. As already pointed out (Bury 1982: 174–7), patients – even when medicine is able to identify the cause of their illness – are always looking for facts or events in their individual or family backgrounds that give meaning to what is happening to them. But the quest of these interviewees had a twist to it: they were trying to explain why the death predicted by doctors 10 years earlier had not occurred – and doctors were still unable to provide an explanation. Does this mean that when medicine cannot provide a satisfactory explanation for a situation, patients persist in the quest for an explanation of their own particular situation?

In the quest for explanations, interviewees insisted on the 'good results' of their yearly blood tests. Many of them said that this had been important from the time when they had learned they were HIV-positive. Given their results, they had gained confidence in the stability of their state of health. In the words of Patrick, 31 years old:

My first results in 1987 didn't worry me that much [...] From test to test, from blood work to blood work, my results were extremely stable, so stable that the idea of living with being HIV-positive gradually took hold.

And Marius, 42 years old, remarked:

My doctor told me there are people who die at the end of from three to four years. At the end of four or five years, I still had nothing. The years were going by, and I had nothing at all.

Their selection for the LTA cohort had shored up this interpretation by underlining how exceptional their situation was. This, in turn, validated their feelings of being 'a little privileged'. As they received the results of blood test year after year, their situation took on meaning and became of interest to French, even international, medical research.

Although interviewees said they usually took precautions during sexual intercourse, they had questions about safe sex, even about its validity. Alban, 30 years old, wondered about this since he never practised safe sex, in particular during fellatio. By saying they sometimes did not take precautions, they wanted to point out that, nonetheless, they had not infected their partner. They thus showed how 'exceptional' they were: After all, were they really 'contagious'? And this reinforced their feeling of being exceptional. Sophie, 34 years old, whose partner refused safe sex for four years, said 'He's lucky, me too since I got away with it. It's true I've wondered, "Do I transmit it?"'

At the same time, interviewees grew aware that they were not alone, that there were others in the same situation. Their 'exceptionalness' thus became a group experience with new horizons: being HIV-positive could become a

way of life with a future – even more so as of the spring of 1996 when new treatments forestalled full-blown AIDS.

But, on the other hand, medical research was looking into their cases precisely because knowledge about HIV was not yet definitive. When referring to their doctors' hypotheses, interviewees talked about cells, proteins or genes; but they also tried to find other explanatory factors in their lifestyles. However, their quest was going round in circles, since none of the selected factors (food, smoking, drinking or 'hygiene' in general) satisfactorily explained the long period of life with HIV. Such explanations turned out to be even less satisfactory for those who had not been much concerned about their health over the years. The difficulty, or even impossibility, of accounting for their situation led participants to look more closely at their physical or bodily traits. Might they not have a resistance because they had previously been sick or, on the contrary, had never been sick?

But they attached the most importance to psychological qualities: 'to have high morale' was the most frequently used phrase for describing, even defining, themselves since 'you either have high morale or you don't'. Sophie declared:

I didn't stop living, but it's part of the fighting instinct to be positive in all senses. You must not let your spirits sag, you have to appreciate life.

One out of three interviewees had been in counselling or psychoanalysis in order to cope with a crisis (depression, separation...) but never simply to keep up their morale.

Beyond these individual, physical or psychological factors, interviewees could – ultimately – only suggest luck. In Patrick's words: 'There's a lottery'. Otherwise, how to explain that, out of his friends who had lived the same life as himself since the age of 17, one person was not HIV-positive, another had died, and he himself was a long-term nonprogressor? Theo, 26 years old, who had been infected 11 years previously, explained:

I worked out this trick, I said 'I believe in luck'. The trick is luck. I play pool, I'm lucky. I'm a good pool-player, but instead of telling myself, I play well, I say, 'I'm lucky'.

Many interviewees wondered whether their luck would hold out: would chance always smile on them? Unable to come up with a satisfactory explanation, they felt privileged to live an exceptional life that could only be set down to luck. It was hard for them satisfactorily to explain a biological situation that was, and still is, inexplicable.

### *Talking about the years gone by*

For interviewees, being selected for the LTA-cohort had proven how exceptional their situation was; and the interview situation itself strengthened this conviction by providing an opportunity for talking about the past.



The interview thus reinforced their sense of being privileged or exceptional. The interview was a time for self-persuasion and the reinforcement of convictions: indeed, interviewees had something exceptional and *were* even exceptional. It provided an opportunity for showing that they had continued living in spite of painful, decisive events, and for telling about how they had constructed their lives in uncertainty.

Interviewees talking about how they had lived as normally as possible all these years. The interview situation was quite different from the one in my previous research, when male participants used the interview to reconstruct their biographies, to testify or to make known the secret of their infection through the sociologist (Pierret 1994).

### **Interviews formulating ...**

By examining how interviewees talked about their past, I was able to bring to light the overall organisation, or form, of each interview. Although nearly all interviewees organised their 'narrative accounts' (Demazière and Dubar 1997) around the idea of going on living as normally as possible, this normality was voiced in two different ways. Some of them talked about the past years in a 'smoothed over' way that minimised difficulties while emphasising that life went on regardless of events. Others told stories punctuated by events that raised questions and called out for meaning, events that could even lead to reorienting their lives or taking new initiatives. However, a formulation of the past by a minority of interviewees corresponded to the situation described by Hyden as 'narrative as illness' (1997), which I have called a sad luck story.

Let me emphasise from the start that these three forms of interviews do not directly or obviously correlate with the objective conditions wherein interviewees found themselves at the time when they learned they were HIV-positive. In other words, whether participants had started out adult life by learning they were HIV-positive or had learned this after the age of 25, when they had become more settled, did not affect the form given to the interview.

What made the situation exceptional was that the interviewees had been selected to be part of a medical research project. Moreover, their participation in the sociological study associated with this project provided them with an opportunity for becoming aware of their exceptional situation as long-term nonprogressors and for talking about it. Their talk endowed episodes out of their past with a subjective meaning. Time had gone by since they had learned they were HIV-positive – years of living day after day as 'normally as possible' without thinking about tomorrow. What counted was the point in time they had reached. But then, because of their selection for the medical research project, and during the interview conducted in that setting, interviewees became aware that they could have imagined – and/or still could imagine – a future.

*...the idea of continuity*

Eleven interviews (a third) were formulated around the idea of going on living from day to day. They intended to show that life had gone on, whatever the price, even suffering. What was important was to cope as best as possible with the contingencies of everyday life without asking too many questions about the future. In these interviews, the past was maintained in, *and* despite, uncertainty and the problems that had cropped up. Since the body had withstood the viral assault, anything that might happen was presented as something that could be overcome. These interviews were organised around the resources tapped to maintain continuity – keeping one's serostatus secret, for instance, forming a couple or becoming an activist. In all cases, normality meant maintaining life's continuity; and the past since the infection was seen as a uniform block of time.

*...a questioning attitude*

Sixteen out of the 30 participants used the interview as a time for raising questions about the years gone by – eventful years with high points that served as reference markers for this reflective, questioning approach. Regardless of what had happened in the meantime, no event could equal the original catastrophe of learning they were HIV-positive. Although not all interviewees voiced unreservedly the idea of changing, and a few of them even refused to, all these interviews were rife with questions about various events; and all of them had questions laden with doubt about certain 'obvious facts'. All this indicated, nonetheless, that some changes had been made.

The LTA project authorised looking back on an eventful past – one marked with events that served as a means for restoring a sense of time. This questioning attitude was expressed differently from person to person. The interviews were formulated around one or more of the following points: alternating periods of withdrawal and revolt; intense involvement in various activities; participation in the LTA cohort; or the construction of an exemplary life. This form of interview centred not on the tapping of resources but, instead, on questions about "meaningful" events. Telling about the years gone by since learning one was HIV-positive, but in a way that raised questions about certain events, was a means of drawing attention to the changes and rearrangements made in one's life so as to prove its normality, or even 'supernormality'. Illness as the starting point for a success story, for 'social values, social acclamation and struggle in a competitive world', as Frédéric's interview will illustrate farther on, can be seen as evidence of a 'supernormal identity' (Charmaz 1987: 287).

*...sad luck stories*

Three out of the 30 respondents took the interview situation to be a time for confiding their troubled feelings. These interviews resembled a long lamentation about successive misfortunes: deaths, loss of an income and

job, etc. Looking back on the past reactivated these events, which did not however serve as reference marks. Time was a long streak of bad luck and misfortune. In none of these accounts, of which an example is given below, was it possible to discover a meaning given to life since the catastrophic announcement of an HIV-positive blood test. These persons saw this announcement as the starting point and cause of their misfortune. As they talked about their life in this setting of an interview for research purposes, they seemed passive, indifferent or even fatalistic towards whatever might befall them. But their position was not like that of patients in mental hospitals who, by weaving 'sad tales' into their accounts of the past seek to make a place for themselves among other patients and to escape from the grips of a total institution (Goffman 1968).

### Interviews as talk about time

What comes into question following the announcement of an HIV-positive blood test is one's self as an 'evolving continuity' (Élias 1996)<sup>1</sup>. Regardless of the form given to interviews about the years gone by since the catastrophic event represented by this announcement, it is as if this time hardly had any importance because what now counted was that these exceptional persons, selected by medical science, were still here to tell how they had lived.

This exceptional situation is what interviewees wanted to make the interviewer understand; only they could do this. To this end, they did not refer to a calendar, to periods or dates. Instead, they mentioned meaningful but seldom dated events that had occurred in the meantime: separations, mourning, informing the family of one's infection, changing jobs or moving, and so on.

#### *Eventful but differently experienced...*

Stirring up memories, as it does, this type of biographical interview provides evidence that 'What we call time means, first of all, a frame of reference' (Élias 1996: 82) made up of various events. As could be seen when analysing these interviews, a single event gives rise to different experiences depending on the person's 'history' as an individual and as a member of various groups. Time was determined on the basis of the happenings that these long-term nonprogressors deemed important in various areas of life. Such events – whether the death of a partner, a new job or apartment, a serious illness or the disclosure of their serostatus – around which interviewees formulated their accounts, 'encyst' themselves in the situation created by the catastrophic event but without deeply modifying its meaning (Leclerc-Olive 1998: 114). In these interviews, such turning points were significant for showing that life had gone on, but each person interpreted them in his/her own way.

Let us look at a few examples to see how differently interviewees reacted to the significant events that had occurred since learning they were HIV-positive.

For all interviewees, and regardless of their past, couples had come together and apart over the years of life with HIV. Out of the 14 persons living with someone at the time of the interview, six were still with the same person as at the time before learning they were HIV-positive; the eight others had formed a couple in the meantime. Out of the 16 respondents living alone at the time of the interview, six had always done so, two were alone since they learned they were HIV-positive; and eight were living alone but had been in a couple for a while. During the years preceding the interview, six out of the 30 interviewees had attended their companion or spouse who had died of AIDS. For one woman, the death of her husband and, the following year, of her daughter set off a chain of misfortunes with no end in sight. For other respondents, life went on as they kept their infection secret or found a new partner.

Eighteen of the 30 persons had moved for reasons unrelated to their serostatus. Five others, infected through drug-use, had left the Paris region in order to cut ties with old acquaintances. Some of them had thrown the drug habit whereas others were still taking drugs under medical control.

Feelings about paper work and administrative demands varied too. Without any qualms, one man took out a life insurance policy once he learned he was HIV-positive, whereas another had recently been upset by the requirement to answer questions about HIV while filling out a medical questionnaire for additional insurance.

The disclosure of HIV-status to one's parents was also understood differently. Ten years after learning he was HIV-positive, one man told his parents following a television broadcast about AIDS. In contrast, one woman after wondering whether she should say anything during a recent hospitalisation for a serious illness, decided to keep the secret.

Another question that remained painful for interviewees was the 'desire to have children'. Two of the women had had an abortion so as not to risk having an HIV-infected baby. A haemophilic man and his wife chose to have a child by artificial insemination.

### *Time and uncertainty: constructing a typology...*

How did interviewees incorporate these various events into their way of talking about the years of life under the threat of uncertainty during an interview in the context of the LTA research project? While analysing these interviews, I was able to bring to light four ways of talking about what we might call 'uncertain time': living from day to day; living an 'identical present', living an 'empty present' and living with a 'possible future'. These four ways of reacting to time will be compared with the three time orientations in Davies' (1997) interviews with 38 persons who, HIV-positive for at least five years, had been recruited out of the 100 participants in the National Long-Term Survivors Group in Great Britain.

The three previously described interview forms have been related to these four ways of experiencing 'uncertain time' so as to draw up a typology of how time was constructed. I have thus defined four mutually exclusive interview categories. This typology makes no claim to generalisation since it is closely related to the sociological study's research context, as already explained. A long excerpt from an interview illustrates each category.

1. Going on day after day

This category is characterised by the relation to uncertain time, a relation constructed from day to day in the immediate present without thinking about tomorrow. This category resembles a strategy that Charmaz (1991: 178) detected, namely: 'living one day at a time is a strategy for managing chronic illness and structuring time but which alters time perspectives'. The category, however, can be used to describe how the past years were lived in the uncertain situation of death predicted a decade earlier. These 12 interviewees felt they had to put up with things as they were, profit as much as possible from the present, and, therefore, make choices. Some had chosen to drop out of school in order to work or write, whereas others had decided to 'throw themselves' into their jobs. This was of relating to time turned up in the two interview forms organised around the idea of continuity and the questioning attitude: regardless of how an interview was formulated so as to present life as being normal, importance was attached to living each moment without thinking about tomorrow.

This way of constructing the experience of time reminds us of Davies' 'living with a philosophy of the present' (1997: 566). By referring to existentialist philosophies, Davies insisted on freedom from the hindrances of daily existence and on the feeling of freedom aroused by the fact that one's life and career are no longer programmed. But in 11 of the 12 interviews that fell into this category in my research, it was not the feeling of freedom from the daily routine that counted, but the determination to continue leading a regular life organised to cope with the impossibility of imagining a future.

Christiane, 42 years old, had been infected following a blood transfusion in 1983. Two years later, she learned she was HIV-positive at a time when she had re-enrolled in higher education and was living with a man to whom she was, at the time of the interview, married. For her, the interview was an opportunity for thinking about, and questioning, both the past and future prospects opened thanks to the LTA project, which had revealed to her how hard it had been to imagine the future during all the years gone by:

I've always felt really ambivalent. On the one hand, I don't allow myself to do certain things, because of it... so I really set limits for myself; and then, on the other hand, I'm finally living like everybody else – I travel to far-off places, work a lot [...]. This ambivalence

sometimes bothers me a lot, because, right now, for example, I'm in a phase, especially since I entered the research project, because, before, I used to tell myself after each blood test, 'OK, I'm fine, I feel fine, I'm doing OK. . . .' I crossed my fingers and said to myself, 'I'm fine.' And since I'm part of the project, I tell myself, 'I'm fine; the progress in therapy is absolutely considerable, and maybe, finally, I'll still be here at 80'. So I had the impression that, 13 years ago, I stopped living. A few simple examples, I don't have supplementary retirement coverage, [. . .] and now I'm thinking, 'If things ever turn out all right, the day when I go on retirement, I'll be in up to my neck'. [. . .] I feel I've drifted a little with the events. I haven't stopped living, but I haven't stopped living because, first of all, maybe it's in my nature and then mainly because, at the start, my husband said, 'So, there's a problem. It's our problem, and we'll keep it to ourselves. Nobody knows about it'. [. . .] I have a really ambiguous attitude. For me, a year that went by without anything meant 'Whew! One more year' and, at the same time, 'One year down, and that much less to live'. That's it. A year was, each time, a little bit like that, and I never much knew whether you should be satisfied with having lived a year a step farther along toward the deadline. [. . .] What was clear was that drifting with the current was sure, but fighting like I had to at the time, I said 'No way'. I have other priorities in life. First of all, I might have to spare myself a little, and then I have a husband, and I want to see him. I was already happy he stayed, that he didn't leave. After all, that wasn't self-evident, I think. So, yea, I kept on keeping on; but I have the feeling that I kept going on, a little bit, by inertia!

## 2. Keeping things the same

Five out of the 30 interviews fall into this category, the most homogeneous one. It combines a single form, the interviews formulated around the idea of continuity, with a relation to time that sought to maintain an 'identical present'. In both the form of the interview and the relation to time, the idea prevailed that nothing should change. Whatever the costs, life had to go on as it had before the infection except for one thing: keeping a watch on HIV. To control 'uncertain time' so that things stay the same, it had been necessary to keep the secret safe. To pursue life as it had been 'before' meant that all was well and normal. This way of relating to time was observed, regardless of how they had been infected, mainly among women and interviewees who were older or had a relatively settled life. This was the only category with a sort of moral imperative.

Davies did not mention this temporal orientation. Might the reason be set down to different characteristics in the French and British groups of long-term nonprogressors? The average time between the infection and the survey was about the same in both groups: nine years in Great

Britain and 9.5 in France. The British were somewhat younger (38.5 vs. 39.9); and there were fewer men (34.9 per cent vs. 80 per cent). The British group was more ethnically diverse (34.9 per cent 'whites' vs. 93 per cent) and less homosexual (31.8 per cent vs. 50 per cent). There were no drug-users in the British group. It is difficult to take this comparison any farther.

Jeanne, 33 years old, had been living with someone for more than 10 years at the time of the interview. Her companion, a drug-user, had infected her nine years previously. She lived outside the Paris region. This excerpt illustrates the interview form organised around the idea of maintaining continuity:

At the time, when I learned that nearly 10 years ago, I thought I'd die, that it was the end of everything. Especially at the time, not much was known about this disease. It was really pessimistic. But too, I was told that no one would be talking about it any more in five years. That's what I heard. So I said to myself, 'Either I die right away, or in five years, it'll be over, it'll be in the past'. Once the five-year deadline had come, well, no headway had been made. It was sort of disappointing to say to yourself, 'Roll on the next five'. And the five years were up, and nothing has changed. Anyway now, I live with it. It's part of my life, even in my deepest dreams. It's always in me. The fear that it'll be known, in my occupational environment for example. [...] I feel that I'm more scared of how others will react than of the illness itself, since I've been living with it for more than ten years. [...] But right now, I feel like I have a disease they're going to heal, that can be transmitted to others, and that keeps me from having children. That's all. Otherwise, I don't feel I have a disease that keeps me from living from day to day. I don't have any health problems. [...] I don't have any problems. They tend to be psychological. [...] I'd be really scared if anyone knew that my friend's HIV-positive. I'm really scared of what people will say; and in a way, I even reject the idea of him being hospitalised, because I think, 'I'll be going. . .'. I've already told him, 'If you're hospitalised, maybe I'll not come. It depends where you'll be [...]'. As for myself, it bothers me a lot, not to go there. So for the time being, I reject the fact that he's been hospitalised. Somehow, it's awful because I tell myself, 'There are some things you have to do in time, you have to do them fast'. What's awful is being scared of others. [...] It's true I went through this phase of being really scared that, I don't know how, but that I could infect someone. That's really scary, so I was always awfully scared that others would know it and blame me later on, that they'd blame me for taking a coffee break at work, for my life at work. Well, now, that's changed [...]. I react a lot in relation to others, being scared of others, scared of them pointing their fingers at me. I can't cope, not with that.

## 3. Withdrawing into one's bad luck

This category combines sad-luck-story interviews with the relation to time described as 'the empty present', *i.e.* time experienced as a stream of overpowering events. The interview situation was used to give form and meaning to an unlucky life-story. In some cases, the streak of bad luck had started even before HIV-infection. The interview was an opportunity for reconstructing a life-story with and around the infection; this corresponds to Hyden's illness as narrative. Three interviews fell into this category. References to a 'happy before', which might have been idealised, emphasised how empty life had become since the infection.

This 'living an empty present', as Davies (1997: 568) has called it, describes the interviews that made no mention, not even a vague one, of any plans. The rift opened in everyday life by HIV-infection was so deep that it could not be mended by the adoption of a day-to-day routine or the maintenance of a degree of normality as though everything was the same. Only the lost past had meaning.

Marcel, 57 years old at the time of the interview, had learned he was HIV-positive 10 years earlier following an unrequested blood test. This self-employed taxi driver had always lived alone in the Paris suburbs. For him, the interview was an emotional experience as he overcame solitude and told his bad luck story.

When I learned I was HIV-positive, I stopped having sex. Since 1986, I've had about a dozen sexual encounters. And now, it's been a year and a half, two years, since I've had any. And I got to say that, right now, I'm soon going to be 57 years old, I don't know if it's my age or something else, but it's on my mind, I want some. I cruise the parks, I don't go to clubs, things like that. I don't know, I'm really shy, and I don't meet the [kind of] guys I like any more. And then when I'm at a cruising spot, I don't want it any more. So it makes me not feel very good right now, because I have a need, and I can't get what I want. And then, there's something else: I've never really kept company with homosex... I am homosexual. I've never really kept company with homosexuals. At the time, before AIDS, there were a lot of heterosexuals, bisexuals, who used to come see/meet, homosexuals. I used to meet that type of guy and get along with them [...]. I've stopped working a lot, I practically don't work anymore. Since I'm HIV-positive, I've slowed down. For four to five years now, I've been tired. I don't know if that comes from the pills I take for my nervous depression or from being HIV-positive [...]. I simply work to be able to buy something to eat, for me and my dog, and that's all. The rest of the time, I stay at home, watch TV, sleep a lot. Every afternoon, I take a siesta for an hour and a half. Besides, I never go to bed before four. My whole life, I've gone to bed at four in the morning, so I can't go to bed earlier. I've always worked at night. So



I'd go to bed at four a.m. and get up at noon. I eat around 1 p.m. I watch TV, then I make my dog piss, and I lie down and fall asleep. Afterwards, I wash and shave, take a shower and watch TV. In the evening, after work, I take my dog out for a walk, and, at the same time, cruise, if I can call that cruising. I go to see whether I'll meet someone I like. Usually I don't meet anyone. There are a few guys I've known for a little while now. I talk to them now and then. That makes me feel better. They're not friends, they're buddies. I've been having depressions for 30 years now. I must get it from my mother. My mother had bad nerves. [...] I lead a very solitary life, I live with my dog. [...] My life is really simple.

#### 4. Constructing an exceptional future

This last category combines the way of relating to time called 'living with a possible future' with two narrative forms: continuity and the questioning attitude. Because these interviewees could imagine a future, their accounts took the form of a quest for an explanation of why they had lived so long. The past had been appropriated and was relatively controlled, as could be heard in the talk about, for example, plans for setting up a business, re-enrolling in college or even bearing a child. What characterises this category is the way of understanding the exceptional situation of being a long-term nonprogressor. This category corresponds to 10 interviews with young men who had been infected through products for treating haemophilia, who had used drugs or who declared they were homosexual.

Frédéric, 35 years old, had learned he was HIV-positive 11 years before the interview. Having broken up with his friend four years previously, he was now living alone. He adopted a questioning attitude during the interview and wept as he sought for an explanation of why he had lived so long. Several phrases he used indicate that, in his relation to time, the future had always been possible, hence his many plans.

I live pretty good. Now and then, when things move, it hurts. And what has moved most painfully over all these years is the people who die around you, not the people but the friends who die around you, and then the close friends whose T4-counts go haywire and who go into treatment and all that. And then a while ago, I managed to consider that being HIV+ in the state I'm in, in other words, as good as you, as anybody else, might have been a chance, because, true, I've lost a little sleep from it, but I've made up for that with millions of other things. I have my own restaurant, I have a wholesale necktie business, I do amateur acting in plays, I exhibit photos, I've taken up piano courses again, AND I don't sleep much, but I surely do a lot, I'm in fashion shows. [...] I would've never had this overdose of energy, I believe, but you can completely trick yourself, if I had not had this disease. [...] Last year, I told my parents. [...] When you're

not scared of your social image, so I'm not scared of that, I control it pretty good, you tell yourself, 'If the people you like know it, the others – to be vulgar – I don't give a shit' [...]. In society, it's true, it was kept top secret for a long time, so it must have not rubbed off on those who never saw me as anything else than a homosexual in good shape, dynamic. [...] There's one thing: a lot of my friends screamed out injustice, but I never did. I always said to myself, 'It's a little logical you caught it.' I have friends my age who got by without a scratch; but I never, never told myself, 'It's not right, it's not normal.' Because it's not right that our generation... I never said to myself, 'Fuck it, why me?' No. I'm level-headed enough to say, 'Pal, that's it. What's done is done.' But it helped me too, the people around me, just to mention my family, often said, even before knowing about it, 'But you're sturdy.' It's true, it's a kind of immense joy to tell yourself, 'You're a force, I have such a force.' [...] When you're hanging in there, when, 11 years ago, you were told you were sentenced to death. [...] But there's a challenge, I mean, when I look at myself, after all, I do pay attention – I jog – and when I see the overwhelming majority of people my age but who don't, don't at all, look as healthy! I mean, however paradoxical it might sound, it's an awful sort of vengeance. Yea, it's strong really strong.[...] So, you have to live with it. And since you have to live, you may as well live as well as possible. I don't come from a family where I know what a depression is, I had that immense chance. [...] And then something else, a simple thing: [...] I said to myself, 'If, some day, illness strikes, I want it to be ashamed of attacking me, I mean ashamed, so it knows exactly what it's going to destroy'. It's crazy, this thing, I mean, isn't it?

## Conclusion

I have ended this article with four different ways of reconstructing the past, which was experienced as uncertainty. These are four ways of living with 'a finite quantity of time which is running down and out'<sup>2</sup>. Existing conceptualisations in the sociology of illness in terms of a biographical rupture (Bury 1982) or of biographical time (Corbin and Strauss 1987, Charmaz 1991) or clock time (Adam 1992) have mainly taken the relation to time and temporal orientations to be constitutive dimensions of the reconstruction of a biography, or identity, among the seriously ill. As already pointed out, the contents of these interviews could not be analysed in terms of biographical rearrangements. Instead, interviewees sought to explain why they had lived so long.

This situation stands out from that of the HIV-positive men I interviewed in 1990–1991, who, living on borrowed time, had a sense of urgency and

tried to control uncertainty. In that situation, reconstructing a personal and collective past *before* the catastrophic announcement of an HIV-positive blood test, was an important part of biographical reinforcement; the sense of belonging to a generation played a major role in this process. For this reason, the past *after* this announcement – being HIV-positive as a temporal dimension – could become an additional resource in the fight against the start of illness and in the effort to construct the hope necessary for living (Pierret 1996 and 1997). For the persons recruited out of the LTA-cohort however, uncertainty was, in a way, a thing of the past insofar as, over the years, they had acquired confidence in their stable state of health, a stability confirmed by their recruitment as part of the cohort. Time was now less uncertain. Under these conditions, they could, in the quest for an explanation, use the past both *since* the catastrophic event and then, during the interview, to imagine a relatively concrete future. In the field of research opened during the past 10 years on the analysis of the relations between time, biography and identity, my current work deals with the relations between research conditions, the formulations given to accounts and the construction of time. Time is no longer understood (as in my previous research) either as a dimension of identity or as a resource for constructing the hope necessary for living.

Two major factors influenced how interviewees from the LTA cohort reconstructed the past: for one thing, their inclusion in a medical research project on the reasons why they had lived for so long with HIV; and for another, the prospects arising out of the new treatments introduced as of the spring of 1996. But it is hard to gauge how these factors came into play. For most of these persons, the exceptional nature of their situation was what was worth studying; that was what they intended explaining during the interview. But unable to provide a satisfactory explanation, they had to fall back on individual characteristics. In these interviews, we mainly hear deeply individual and individualistic life-stories, differing from my previous research when each male interviewee reworked and integrated his life-story in his reference group's history, as part of the past of his generation. In effect, the analysis of the more recent set of individual interviews needs to be incorporated in the collective time of the historical narrative of illness.

*Address for correspondence: Janine Pierret, Centre de Recherche Médecine, Sciences, Santé et Société, CNRS/INSERM/ÉHÉSS, 182 bd. de la Villette, 75019 Paris, France*  
*e-mail: Pierret@ext.jussieu.fr*

## Acknowledgements

I should like to thank the editors and anonymous referees for their helpful comments. The French National AIDS Research Agency (ANRS) provided funding

for this research. This article has been translated from French by Noal Mellott, CNRS, Paris.

## Notes

- 1 In his essay on time, N. Élias has analysed the complex relations between a normalised social continuum that serves as a frame of reference and the evolving continuity that each person represents. Only in highly individualised societies can the person use his/her own life as the frame of reference for determining the timing of other changes (Élias 1996: 54).
- 2 These four typological categories do not, however, lie at the same level as the 'theories' proposed by Crossley (1997) in her qualitative research on long-term nonprogressors in Great Britain. She distinguished two types of theories on the basis of involvement in activities and the ability to tap resources so as to face up to the diagnosis: interpersonally oriented, intrapersonally/intrapsychically oriented. In constructing the four types, I have tried to place the particularity of each person's account in the social and symbolic spheres that he/she shared with others.

## References

- Adam, B. (1992) Time and health implicated: a conceptual critique. In Frankenberg, R. (ed) *Time, Health and Medicine*. London: Sage.
- Aïach, P., Kaufmann, A. and Waissman, R. (1989) *Vivre une maladie grave*. Paris: Méridiens-Klincksieck.
- Augé, M. (1984) Ordre biologique, ordre social: la maladie, forme élémentaire de l'événement. In Augé, M. and Herzlich, C. (eds) *Le sens du mal. Anthropologie, histoire, sociologie de la maladie*. Paris: Éditions des Archives Contemporaines.
- Bury, M. (1982) Chronic illness as a biographical disruption, *Sociology of Health and Illness*, 4, 167–82.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects, *Sociology of Health and Illness*, 13, 451–68.
- Carricaburu, D. and Pierret, J. (1992) Vie quotidienne et recompositions identitaires autour de la séropositivité. Paris, CERMES-ANRS.
- Carricaburu, D. and Pierret, J. (1995) From biographical disruption to biographical reinforcement: the case of HIV-positive men, *Sociology of Health and Illness*, 17, 65–88.
- Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill, *Sociology of Health and Illness*, 5, 168–95.
- Charmaz, K. (1987) Struggling for a self: identity levels of the chronically ill, *Research in the Sociology of Health Care*, 6, 283–321.
- Charmaz, K. (1991) *Good Days, Bad Days: the Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.
- Corbin, J. and Strauss, A. (1987) Accompaniments of chronic illness: changes in body, self, biography and biographical time, *Research in the Sociology of Health Care*, 6, 249–81.

- Corbin, J. and Strauss, A. (1988) *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco-London: Jossey-Bass Publishers.
- Crossley (Davies), M. (1997) 'Survivors' and 'victims': long-term HIV-positive individuals and the ethos of self-empowerment, *Social Science and Medicine*, 45, 12, 163–73.
- Davies, M. (1997) Shattered assumptions: time and the experience of long-term HIV-positivity, *Social Science and Medicine*, 44, 5, 561–71.
- Demazière, D. and Dubar, C. (1997) *Analyser les entretiens biographiques. L'exemple des récits d'insertion*. Paris: Nathan.
- Élias, N. (1996) [1984] *Du temps*. Paris: Fayard.
- Fox, R. (1959) *Experiment Perilous: Physicians and Patients Facing the Unknown*. Philadelphia: University of Pennsylvania Press.
- Frank, A.W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Gerhard, U. (1990) Qualitative research on chronic illness: the issue and the story, *Social Science and Medicine*, 30, 11, 1149–59.
- Giddens, A. (1979) *Central Problems in Social Theory*. London: Macmillan.
- Goffman, E. (1968) [1961] *Asiles. Études sur la condition sociale des malades mentaux*. Paris: Éditions de Minuit.
- Herzlich, C. (1969) *Santé et maladie. Analyse d'une représentation sociale*. Paris-La Haye: Mouton.
- Hyden, L.C. (1997) Illness and narrative, *Sociology of Health and Illness*, 19, 1, 48–69.
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Leclerc-Olive, M. (1998) Les figures du temps biographique, *Cahiers Internationaux de Sociologie*, 104, 97–120.
- Pierret, J. (1994) Dites-leur ce qu'il ne m'est pas possible de dire: Je suis homosexuel et séropositif, *Discours social/Social discourse*, 6, 3–4, 33–45 + bib.
- Pierret, J. (1996) Maladie, sciences et société: l'expérience des personnes atteintes par le VIH, *Natures, Sciences, Société*, 4, 3, 218–27.
- Pierret, J. (1997) Un objet pour la sociologie de la maladie chronique: la situation de séropositivité au VIH? *Sciences Sociales et Santé*, 15, 4, 97–120.
- Pierret, J. (1998) Vivre longtemps avec le VIH: récits sur la longue durée de vie et reconstruction du temps biographique. Paris, CERMES-ANRS.
- Polkinghorne, D.E. (1988) *Narrative Knowing and the Human Sciences*. New York: State University of New York Press.
- Schneider, J. and Conrad, P. (1983) *Having Epilepsy: the Experience and Control of Illness*. Philadelphia: Temple University Press.
- Strauss, A. and Glaser, B. (1975) *Chronic Illness and Quality of Life*. St Louis: Mosby.
- Williams, G. (1984) The genesis of chronic illness: narrative reconstruction, *Sociology of Health and Illness*, 6, 2, 175–200.