

HIV, mortality and the self

Sebastian Rinken

London School of Economics, LSE Health and Social Care (United Kingdom)

Introduction

As some observers have noted early on, the HIV/AIDS pandemic has, since its emergence in 1981, «touched on almost all aspects of society» (Fineberg 1988). In a first sense, this means that this condition is «an extraordinarily useful sampling device» for the social scientist (Rosenberg 1989): it provokes reactions, which make the constitution of social reality visible with particular clarity, thus constituting a valuable analytical tool. In a second sense, it means that AIDS may «also *reshape* many aspects of society, its institutions, its norms and values, its interpersonal relationships, and its cultural representations» (Nelkin/Willis/Parris 1991: 2). HIV “touches on” society in this double sense of having analytical and – potentially – substantive effects.

In the following, I will apply this general line of inquiry to the contemporary Western form of subjectivity. By relating the three concepts mentioned in the title to one another, I should attempt to shed light on the contemporary form of subjectivity – i.e., the historically and culturally specific manner in which contemporary Western individuals may establish a sense of identity. The analysis of biographical narratives by people with HIV/AIDS will be used as a tool in order to gain insights into the state of contemporary subjectivity. The close association of HIV with the prospect of finitude will be crucial for this condition to assume the status of a privileged analytical tool regarding the contemporary Western self.

My knowledge and methodology, as well as some of the terminology used in this article (including the very concept “*form* of subjectivity”), are inspired by the last period of Michel Foucault’s work, namely, his research on historically and culturally specific experiences of sexuality (Foucault 1984a, 1984b). The idea is to grasp the *historical a priori* of basic human experiences – i.e. the cultural and historical specificity of the framework for making these experiences, which is generally taken for granted in a given society. For a more detailed description of the way in which the research pre-

sented in this article is inspired by Foucault's work, please refer to a recently published monograph (Rinken 2000).

The argument that I will develop entails a rather straightforward – if implicit – statement regarding the contribution of medical anthropology to general anthropology. Let me anticipate this statement in an explicit fashion. I suggest that research on the ways in which contemporary Western individuals can make basic human experiences, such as disease and mortality, constitutes a crucial contribution to the reflection on the contemporary Western way of being. I consider such self-reflexive inquiries on the historical and cultural specificity of contemporary society to be, in turn, the intellectually most challenging task of the social sciences in general and anthropology in particular.

In the following, I will first discuss the nature of life with HIV as an experience of mortality. In a second step, I will explore the relationship between historically specific forms of subjectivity, on one hand, and the strong awareness of a limited life expectancy, on the other. Third, by discussing two exemplary cases, I will present the empirical results of the research that matter most in the context of the argument presented here. Finally, I will bring the basic conceptual elements of this research (HIV, mortality and the self) together by suggesting a “diagnosis” of contemporary Western subjectivity.

To avoid misunderstandings, I would like to make a few remarks about the sense in which I refer to death, mortality and finitude throughout this article. The privileged role granted in my analysis to this aspect is not meant to imply that it is the only one that matters for people who live with HIV/AIDS. Other highly relevant problems include the possible stigmatisation of HIV's main transmission practices and the endurance and management of the manifold afflictions, which may hit the infected. I have applied a selective research strategy, rather than aiming at an exhaustive description of life with HIV. In addition, my emphasis on mortality is not to be confused with the notion that, within a time frame still to be defined more precisely, all or almost all HIV-positives are to die. Terms such as “mortality”, “the problem of mortality” and “the prospect of finitude” have nothing to do with mortality rates as such; they are used as synonyms of “the *thought* of mortality during lifetime”.

To some extent, the problem of death will thus remain abstract throughout this article. In my use of the term, “experience of mortality” does not refer to the process of dying, i.e. the last weeks or days. Rather, it refers to the recognition of having to die *some day* – with this day being expected or

feared to arrive *too soon*. Admittedly, the distinction is fragile. Yet, the recognition of one's own mortality during lifetime is irreducible to preparing oneself to actually die. The experience of HIV-positivity is special in this respect. Other conditions which evoke a strong awareness of mortality, such as diagnosis of advanced-stage cancer, are likely to cause death within a much shorter time-span than that which people with HIV have, on average, after having been intensely confronted with the prospect of their own finitude. As compared to people affected by fatal epidemics of the past (such as influenza or the plague), people with HIV typically have relatively more time «to reflect on their condition» (Ryle 1992).

HIV as a symbol of mortality

Since the introduction of anti-retroviral combination therapies in the mid-1990s, HIV infection has increasingly come to be perceived as a chronic, manageable condition – to the extent, that is, to which those treatment options are available to the affected. The Vancouver AIDS Conference in 1996 constituted a benchmark in terms of establishing “Highly Active Anti-Retroviral Therapy” (HAART) as a viable treatment option. In order to avoid a misled notion of HIV now being fully “under control”, it is of course important to be aware of the clinical limitations that the current treatment offers. These include the possibility that the Human Immunodeficiency Virus may develop resistance against one or several of the components of a drug “cocktail” (potentially triggering a dramatic decrease in treatment options), that the drugs’ effectiveness may diminish in the long run, or that their toxicity may cause intolerable side-effects. In addition to this note of caution, it is also important to stress the geographical limitations of combined anti-retroviral therapy. As is well known, the lack of basic medical care, not to mention huge problems in making these extremely expensive HIV/AIDS treatments available to developing countries, is bound to contribute to the perpetuation of the devastating impact of this disease in large parts of the world, especially in sub-Saharan Africa. That said, however, it seems likely that the current trend toward a substantial improvement in treatment options and, subsequently, the affected people’s life expectancy, will – in industrialised countries – result in removing the “death sentence” image that was initially attached to HIV and AIDS.

Throughout the first 15 years or so of the pandemic, though, HIV/AIDS unquestionably constituted a powerful symbol of mortality not only in developing countries, but in Western industrialised society as well (to which

the observations contained in this article are limited). At present, this symbolic dimension is in the process of being re-established as a boundary between the highly industrialised and the so-called developing world. In the pandemic's early years, however, this boundary primarily divided social groups within Western society from one another. The initial emphasis on the link between practices that are limited to specific subgroups of the population (such as drug injection or homosexual intercourse), on one hand, and the risk of getting infected, on the other, provided much-needed reassurance to the wider population regarding their own vulnerability. For at least the first 15 years of the pandemic, the close association of HIV and AIDS with death and dying clearly was one defining factor for the relations between the affected and their social environment. The symbolic status of this condition as a synonym of premature death affected the social relations of the HIV-seropositive in many ways, including the fear of disclosing one's serostatus to family, friends or colleagues, and the manifestation of unhelpful or even negative reactions to such (deliberate or, at times, involuntary) acts of disclosure. While the social science literature generally describes these phenomena as caused by the manifestation or fear of moral stigmatisation in relation to HIV's main transmission practices, they can all result primarily or even exclusively from HIV's association with premature or even imminent death (Rinken 2000, 161 ff.). Even in special social environments such as self-help groups, created explicitly by and for HIV-positive people in order to protect themselves against discrimination and to provide mutual support to one another, a "hierarchy of mortality" in relation to immunological markers of disease progression can be observed (Rinken 2000, 113 ff.).

More important still in the context of the argument presented here, the close association of HIV with human mortality also tended to determine the perception of an HIV positive diagnosis on the part of the individual receiving the news. Throughout the pandemic's first 15 years or so, when receiving a "positive" HIV antibody test result, the affected individual typically felt that her or his life expectancy had suddenly diminished dramatically; in many cases, he or she even expected imminent death.

Apart from similar findings in other studies, this is what happened to almost all the people interviewed for the research project the results of which are reported here. In the spring of 1993, I conducted in-depth interviews with 21 individuals with HIV or AIDS based in Florence or Milan (Italy), including men and women from all relevant transmission groups⁽¹⁾. My interviewees' age at the time of diagnosis ranged from 19 to 48 years, and the year of diagnosis ranged from 1983/4 to 1992 (with twelve cases diag-

nosed in 1987 or earlier). From indications given in the course of the interviews, I can infer that more than two-thirds of my respondents had been infected with HIV for at least five years before the time of interview⁽²⁾.

This study is thus situated at a precise point in the history of the HIV-pandemic: the fieldwork was conducted before the development of HAART. With just one or two exceptions, my interviewees shared the social perception of HIV/AIDS that was dominant at that time, intimately linking this condition to the prospect of finitude. Before receiving the diagnosis, my respondents had (again, with just a few exceptions) also shared the generalised confidence of living on to old age that, according to many observers (e.g. Ariès 1974), has contributed to turning death into a “taboo topic” in 20th century Western society. In combination with their youth (two-thirds of my interviewees were between 19 and 29 years old when receiving the diagnosis), this taken-for-granted nature of longevity made the sudden confrontation with the prospect of premature death all the more traumatic.

The event of diagnosis hence constituted a (indeed, usually *the*) crucial turning point in the lives of my interviewees. Due chiefly to its initial association with imminent death⁽³⁾, the diagnosis of HIV marked a clear distinction of a “before” and an “after” in their lives. In reaction to the first question (which was the same in all the interviews), namely, the request to tell me something about life before HIV, almost all my interviewees established a biographical narrative structured in terms of the difference between the *before* and the *after*. Almost all my informants had perceived the diagnosis of HIV as a watershed event, a perception that they recounted in reaction to my initial question. The interviews conducted for this research permit the identification of five modes of self-constitution as mortal beings – five ways (“ideal” types in the Weberian sense) of relating the periods *before* and *after* diagnosis to each other. These are invalidation, reinforcement, switch, void, and continuity.

The “invalidation” and “reinforcement” patterns potentially form a sequence – yet the development from the first to the second is by no means automatic. Representatives of the invalidation pattern report a lasting loss of the self, which had characterised their life before diagnosis. Representatives of the reinforcement pattern had perceived a similar loss of self as an immediate effect of diagnosis – but they have since overcome this crisis by re-connecting with that previous self-definition and accepting it as again valid, which develops a sense of continuity with the period preceding diagnosis. Most of my respondents by far belong to these two patterns, defined by a sharp contrast between the *before* and the *after* and a strong desire to

retrieve key elements of that *before* (a desire that is accomplished in the reinforcement mode). Many “reinforcement” interviewees had got in touch with a self-help group soon after receiving the diagnosis; in many cases, their identity work as an HIV-positive person is related to a shared group identity as homosexual men.

Specific background experiences may lead to particular experiences of diagnosis. While the loss of one’s old self-triggered by the diagnosis of HIV is usually (as in the invalidation and reinforcement patterns) deeply regretted, it may actually be welcomed by the affected individual especially if the lost aspect of self was valued negatively even before the diagnosis. The sudden *switch* of a central aspect of the old self-definition to its contrary is thus fully acceptable and constitutes the basic structure of that individual’s biographical narrative. A second contrasting pattern (*void*) may result from prolonged intravenous drug-use, especially when it had constituted the sole centre of conduct throughout youth and young adulthood. The knowledge of HIV-positivity may then enhance the feeling of emptiness left by that habit and not the loss of a highly cherished self; the individual is confronted with the perception of lacking a distinctive self-definition. Finally, while most of my respondents spontaneously associated the knowledge of having HIV to the prospect of imminent death, some conceived the development of their self as continuous across that moment: diagnosis does not constitute a biographical watershed here. Among my interviewees, the exemplary case for the *continuity* pattern is a person with haemophilia: life-long experience with this disease had taught him not to anticipate potential future distress, but rather wait and see.

My use of the research interview as an analytical tool with a view to contemporary Western subjectivity relies on the combination of two crucial features of the HIV experience. Speaking in general terms, HIV combines an extraordinarily strong association with the thought of mortality at the time of diagnosis and a relatively long time of survival afterwards. Relative, that is to say, not only to the affected individual’s expectations immediately after diagnosis, but also to other medical conditions that are commonly classified as terminal. While it is possible, after the initial shock, to retrieve some trust in the future and to again develop plans and projects, the idea that you may be *running out of time* is bound to persist. For the generation of people with HIV/AIDS represented by my interviewees, the future never quite recovers its previous taken-for-granted quality. Even while recovering the strength to engage in projects with a prominent future-dimension, the individual has to render his or her self-definition compatible with the possibility that death may be close.

Awareness of mortality thus has to find a place within the affected individual's self-construction – in a double sense. First, the biographical self-construction that is established at a given time can be sustained as valid only if it is compatible with the possibility that there may not be enough time to substantially review it in the future. Otherwise, any reminder of one's finitude may cause depressive crises due to the contrast between that self-definition and the thought of mortality – and life with HIV abounds in such reminders. Second, that self-construction has to accommodate the effects of the event which first provoked the intense awareness of finitude (namely, as a rule, the diagnosis of HIV). For individuals living with HIV or AIDS, the challenge of biographical self-construction is constituted by this double matrix of lasting awareness of finitude, on the one hand, and past disruption (if diagnosis was indeed perceived as a disruptive event), on the other.

I suggest that the combination of these two features constitute a vantagepoint for the analysis of contemporary Western subjectivity. To make this point plausible, I will now briefly outline the current sociological debate on the contemporary Western self. Building on essential contributions *to* and some observations *on* that debate, I will then return to the question why I consider the biographical narratives of people with HIV to be an excellent basis for making observations regarding the contemporary Western self.

Biographical self-construction in contemporary Western society

In recent years, a large number of sociologists and social psychologists have contributed to the debate on the state and development of subjectivity in contemporary Western society. The ongoing discussion on the self is imbued with concepts such as fragmentation, fluidity and reflexive construction. Its empirical basis is the observation that, in order to function within an increasingly fragmented and unstable world, the self has in turn become increasingly fragmented and unstable. As a result, the classical modern conceptualisation of the self as based on a sense of continuity and coherence in relation to personal attributes⁽⁴⁾ is being received with growing scepticism.

In a range of literature commonly labelled as “post-modern”, the self is described as a chameleon that consciously selects both professional and private commitments; the lifetime perspective is dissolved into a loose sequence of selves. This “post-modern” conceptualisation relies on the as-

sumption that the self's malleability includes the future. In addition to the idea that individuals fashion themselves regardless of past commitments, it is assumed that the self is "liquid" also with a view to the possibility of future revisions, taking for granted that any element of the present self definition may be changed when appropriate. A similar assumption is made by leading representatives of the alternative school of thought, which defends the idea that the contemporary self preserves some nucleus of perceived coherence and stability. Even these latter authors assume that the self has to adjust to the increasing flexibility and complexity of the social world by becoming in turn increasingly flexible and multi-faceted. Self-construction is supposed to proceed by means of "biographical incrementalism" (Schimank), i.e. the temporary adjustment of one's self-definition to largely contingent life situations. From the outset, such "incrementalist" self-definitions are established with a view to the possibility of their future revision.

For the assumption of future malleability to be tenable, however, people need to be confident that they will have a rather long span of life ahead. This is a blind spot of current theories of the self: a basic point that is taken for granted. This blind spot is characteristic not just of the contributions by advocates of the post-modern self, but of the whole debate. The current debate on the self does not address the issue of how the awareness of a strongly limited life expectancy may affect the self-construction of contemporary individuals; it neglects the finite nature of life. Even those authors who come relatively close to addressing the problem of biographical self-construction in the awareness of mortality, such as Zygmunt Bauman and Anthony Giddens (to mention one representative of both the "post-modern" and "late-modern" camp, respectively)⁽⁵⁾, fail to take the prospect of mortality seriously.

In his *Mortality, Immortality and Other Life Strategies* (1992), Bauman distinguishes between a modern and a post-modern way of confronting life and death, which generate distinct types of selfhood. According to Bauman, transcendence of the human being's finite nature is a necessary prerequisite of any cultural creation. This is to say that mortality is *the* constitutive feature of social institutions and cultural creations – yet this generative power is most forceful «precisely when we manage to live *as if* death was not or did not matter» (Bauman 1992: 7). All meaning is due to our condition as mortal beings – yet it relies on this truth being bracketed: «Memory of illegitimate birth must be erased if noble life is to be practised with ease» (Bauman 1992: 8).

This being the general situation, specific strategies of forgetfulness are employed in different periods of history. As Bauman argues, modernity de-constructs mortality into a multitude of afflictions that can potentially be dominated by science – whereas in post-modern time, immortality is de-constructed into a multitude of achievable satisfactions. In modernity, the ultimate threat vanishes from view as a result of its de-composition into the failure of specific organs. In post-modern time, by contrast, «the ultimate perfection may dissolve and vanish from view» as a result of specific moments of happiness: «Immortality is as nomadic as the nomads it serves.» (Bauman 1992: 164) In biographical just as in historical time, the modern obsession with continuity and coherence is giving way to a new condition: the post-modern nomad constructs his or her identity «until-further-notice» (Bauman 1992: 167). Life turns into a series of unconnected experiences: the past no longer binds the present, just as the present ceases to bind the future. As Bauman suggests, the only lasting feature of post-modern identity is its transitory nature: the self is experienced as a sequence of potentially reversible transitions.

Turning to a social theorist who believes that the contemporary Western self represents the full development of tendencies inherent in modernity, Anthony Giddens' *Modernity and Self-identity. Self and Society in the Late Modern Age* (1991) contains an account of the relationship between contemporary institutional developments and the mechanisms by means of which individuals attempt to generate a sense of personal coherence and direction. The contrast between Giddens and the post-modernists is not semantic: Giddens stresses that a sense of continuity and unity remains a defining feature of self-identity even in post-industrial society. Yet such a sense of coherence is not an objective quality – it is the result of an ongoing process of assessment. Just like all other sorts of knowledge, self-identity has become a reflexive enterprise:

«It is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography.» (Giddens 1991: 53).

While self-definition in terms of status positions or stable social roles was common in static societies, modernity has turned the individual's own lifetime into the main entity in relation to which self-definitions may be established. This ongoing process of biographical self-construction takes place in an institutional environment characterised by the dissolution of cultural traditions, the pluralisation of life-worlds and lifestyles, the generalisation of doubt with regard to the validity of any sort of knowledge, the mediation of experience, and the generalised aware-

ness of multiple risks. The aggregate effect of these factors on the late modern individual, Giddens argues, is an exacerbation of the reflexive nature of the self-process. The multiplication of contexts, choices and potential calamities fosters a growing concern for self-construction in terms of one's life-trajectory, a growing concern with the reflexive planning of one's own life.

Matters of life and death hence play a central role in Giddens' account of modern subjectivity: the very concept of life-trajectory implies life's finitude. Yet, the conscious reflection on one's own finitude does not take on systematic relevance for his analysis of the late modern self. As employed by Giddens, the concept of life-trajectory conceives the future as a horizon of possibilities, rather than taking finitude into account as a potential limit. Knowledge, it has been said, has taken on a hypothetical, "until-further-notice" character in modern time – including the knowledge that an individual may establish about his or her self by way of biographical self-construction. In any given moment of self-construction, Giddens' late-modern self establishes his or her sense of identity only provisionally – in the belief, that is, that the present construction may be revised in the future. Acute awareness of finitude is at odds with this premise.

Current theories of the self assume that the individual can take an extended future life for granted. To some degree, this assumption simply reflects the unprecedented average life expectancy in contemporary Western society. Yet, as we have seen above, this assumption is untenable for people with HIV or AIDS as long as this condition still represents an extraordinary existential crisis for the affected; put cautiously, it has been untenable for the generation of affected individuals represented by my interviewees. From the perspective of people with HIV, the future's uncertainty has to be taken into due account. There may be no time to establish a different construction of self.

From the contrast between ordinary people's confidence in a long life expectancy, on one hand, and the situation of people who have received a "terminal" medical diagnosis, on the other, one may conclude that a biographical self-construction established in the absence of such confidence is too existentially distinct from the general frame of experience to allow for observations regarding a given culture's *form* of self-construction. I suggest that this conclusion be misled. Unlike nutrition, for example, awareness of mortality does not constitute a specific sphere of experience as against others; rather, it sheds light on all of an individual's possible experiences.

To use Bauman's formulation (1992: 2), «whenever being speaks of that other, it finds itself speaking, through a negative metaphor, of itself». As long as we speak and think, we are not yet dead. To think or speak of one's own mortality basically means to reflect on one's life and self. This reflexive perspective differs from ordinary people's reflexive construction of self in that the future is far more uncertain (by "ordinary", I mean people who take an extended life expectancy for granted). Yet, people who are acutely aware of their own mortality will still apply their society's specific cultural framework when thinking about their lives. While having to adjust for the future's fragility, the cultural blueprint of their self-reflections is not invented by them on the spot. Rather, when constructing their lives and selves in the awareness of *being mortal*, they enact historically and culturally specific patterns of self-construction that are available to them in their society.

As an alternative interpretation, then, I suggest that in any given society, there is a close link between the experience of mortality, on one hand, and the general form of subjectivity, on the other. At any given point in history, specific circumstances may cause a more or less vast part of the population to develop an acute awareness of mortality. Rather than dropping out of their society's cultural framework by virtue of this heightened sensibility to the problem of mortality, I suggest that they enact that pattern in a particularly clear manner. The self-construction of people who are intensely aware of their own mortality may be extraordinarily revealing with regard to the form of subjectivity that is dominant in a given society. By "form of subjectivity", I mean the historically distinctive sort of self-relations which people may establish when reflecting on their lives and selves.

I would like to illustrate this idea by referring to the Stoic experience of mortality as described and advocated nearly 2000 years ago by the Roman philosopher Seneca. Seneca famously recommended the contemplation of one's own mortality as a spiritual exercise. In his letters to Lucilius, for example, he invites his disciple to reflect daily upon the best way of exiting life: «The only goods which are truly enjoyable for their owner are those for the loss of which he has successfully prepared his soul» (Luc. I.4.6.).

By means of exercises of thought such as the contemplation of death, the Stoics sought to raise their existence above the level of ordinary life. These spiritual exercises were designed to rid the mind of bad habits of thought – such as the idea that death may be an evil. Excellence in such intellectual asceticism would bring about one's transformation into a sage – a state as

close to divinity as can possibly be aspired to by human beings. Thus, for the Stoics, self-constitution as mortal involves *change* relative to the ordinary condition of their contemporaries. Yet to us, it also reveals a way in which Greco-Roman subjectivity differs categorically from ours. The sage's self was conceived as a reproduction of the divine order of Nature. As Pierre Hadot has stressed, a feeling of belonging to this all-embracing order of the Cosmos constituted, in Antiquity, a necessary condition for any action to be taken on one's self (Hadot 1988: 263). The contrast with the contemporary self's situation is evident: we are neither able to conceive our environment as the eternal Cosmic order, nor our selves as black boxes potentially ready to reflect that order.

In contemporary Western society, the acute awareness of one's own mortality sets an individual apart from the general population in a particularly strong way. This is especially true if young people make that experience. Yet, I assert, precisely this break with respect to the taken-for-granted character of an extended life expectancy provides a precious analytical tool with a view to contemporary Western subjectivity. This is even truer if, as in the case of HIV positivity, the intense awareness of finitude has come about in the context of a highly disruptive life event – namely, the event of diagnosis. When establishing his or her present sense of identity in relation to a biography marked by the event of diagnosis in terms of a *before* and an *after*, the individual has to take account of the fact that life and self could have developed differently in the absence of that event. HIV's double matrix of disruptiveness and lasting awareness of finitude confronts the individual intensely with that paramount problem of modernity, namely, contingency. If the test for HIV serostatus had turned out "negative", the present (including the present sense of identity) could be substantially different. The experience of HIV/AIDS exemplifies and exacerbates the threats posed in contemporary Western society to the perceived coherence and stability of the self.

Due chiefly to its association with finitude, the diagnosis of HIV is bound to shape the individual's sense of self *after diagnosis* in important ways. In retrospect, diagnosis may thus become visible as a contingent event that left a decisive mark on the self. Visible, that is, not just to the social scientist who studies the biographies of people with HIV, but to the affected persons themselves. The crucial question is how this event is related to the individual's present sense of self. What role is attributed to the experience of finitude (and the key event which triggered that awareness) with regard to the overall development of the self?

Self-actualization versus self-transformation

To address this question, I will now discuss exemplary cases of the two types of overall effect of the HIV experience on the individual's self that have emerged from the interview material: self-actualisation and self-transformation. For one of these two types, namely, self-transformation, there is actually only one clear example among my respondents – who also happens to be the exemplary case of the switch pattern⁽⁶⁾. Interviewee Francesco recounts that, in the context of a dramatic health crisis, his personality changed suddenly and substantially. While conceding that «usually, you know, the character does not change in just one moment», Francesco reports that this is what happened to him. His biographical narration is structured in terms of the *before* and the *after* marked by a sudden change of his self – a change to the better in terms of his ability to connect to his social environment.

Let us have a closer look at the event that caused Francesco's change, which happened about ten months after his HIV diagnosis. As further blood work had revealed soon after he first received the news of HIV-positivity, his CD4-count was already down to almost zero; Francesco was thus confronted with the diagnosis not just of HIV, but of advanced-stage AIDS. Francesco says he became scared by the thought of imminent death when, several months later, he got trapped on a remote island without proper treatment for the *candida* which kept him from eating sufficiently (in a previous *candida* attack, he had lost 17 kilos in weight). He also felt intense pain because of an acute infection.

In this context, the key moment in his narration is the collapse of the «bubble» in which he had felt to be wrapped up, and by which he felt cut off «from everything and everybody», including his lover and his brother, who were travelling with him. His brother told him that, if he felt so bad that he seriously feared to be dying, he should either *react*, or else start to prepare himself for the «journey». Francesco reports that this clear-cut alternative «triggered the change». Given that he did not at all feel ready to die, he chose «reaction».

– «In that moment, I was really scared of being about to die. Because I did not have the [appropriate] medical drugs, I had this candida [in the mouth] which, I said, 'if I lose some more weight there is nothing left', because I was already very slim, you know? So, so, like that (...)»⁽⁷⁾. Then, once I had succeeded in interrupting that vicious circle, nothing, I started to do well – to do well: to recover, to do better. I started to feel an appetite again, you see. The situation started to turn normal again.»

- «Also because you talked?»
- «*Because I started to talk. (|||) Because before, I absolutely did not manage to talk (|||) about how I felt, you see. It really was as if I had a wall instead of a brain, you see, which means [my brain] did not work, it did not.*»
- «A wall toward the others or toward yourself?»
- «*With regard to the others and toward myself.*»
- «Both?»
- «*Both, you see, because as far as I'm concerned, they are closely linked, because I have never been a very eloquent, very open, very, as it is called, extrovert sort of person. I always figured out everything on my own, whereas, in contrast, [in that period], it was, it was like that, I did not even think about anything, you see, I did not even spend my time reflecting on things.*»
- «[Your brain] did not work too much?»
- «*It didn't work any more, no, so both the, let's say ... the critical stance toward myself and the ability to express myself to others were both paralysed. You see? That's a bit, let's say, my experience of before and after, because now, for example, even if usually, you know, the character doesn't change in just one moment, but yes, [now] it is much easier for me to talk with others.*»

Before, Francesco says, «*I have never been a very eloquent, very open, very, as it is called, extrovert sort of person*». Strikingly, this *before* refers not only to the period immediately preceding the event recounted here (at the time of which he was 46 years old), but it extends to various decades of Francesco's life: «*I always talked little*»; «*there has always been this ... this handicap (...), even when I was a boy, when I was 17, 18, 20 years old*». His sudden change of personality regards not just that acute crisis, but his sense of identity throughout his life.

«*And I am doing much better, because I am much calmer, more relaxed, you see, – that's to say, almost everything changed, – everything changed, in short, it changed for the better, I have to say.*»

While from the observer's perspective, it is easy to label this perceived change for the better a “secondary gain” that makes his very complicated health situation easier to bear, the truly striking observation is that Francesco's *past* sense of self comprises all of his adolescence and adulthood up to the age of 46.

Francesco's report thus is a very clear example of the switch pattern – i.e., a neat break between *before* and *after*, without any desire to return to the former. Now, for the purposes of the argument that I wish to present here, it is crucial to stress that this structure of the biographical narrative in terms of a *switch*, on one hand, and the interpretation of that biography in

terms of *self-transformation*, on the other, are *not* the two sides of just one coin. In other words, Francesco's assessment of HIV's impact on the development of his self could have been different, despite the basic structure of his narrative in terms of *switch*. In the context of my argument, a crucial feature of Francesco's account is the absence of any indication that he believes to have now finally achieved access to his "true" self, for example by describing his dramatic crisis and change as a "self-revelation". Francesco limits himself to the statement that he has changed suddenly in reaction to the intense dread of death that came about in the aftermath of his HIV-diagnosis. «*There really was a turning point, yes ... Really a remarkable change, as I told you, as compared to how I was before, in short.*»

This matter-of-fact description of successive identities is in sharp contrast with the way in which a variety of other respondents, including representatives of all four remaining patterns of biographical self-construction (invalidation, reinforcement, continuity and void), assess the impact of HIV on their lives and selves. In all those cases, the self-definitions *before* and *after* are distinguished not only in terms of a preference for one of the two (as in the case of Francesco), but a judgement as to their degree of approximation to the "true" self. Before elaborating further on the difference between self-transformation and self-actualisation, let us have a look at an example of the latter.

Giulio is an exemplary case of the invalidation pattern. Just like Francesco, his biographical narrative establishes a neat distinction between the *before* and the *after*; just as in Francesco's case, this distinction is related to contrasting self-definitions regarding his attitude toward the social environment. In the case of Giulio, though, the self-definition that is valued positively is the one that is perceived as *lost*. Rather than accepting his new self, Giulio keeps deploring the loss of his old one – even though, at the time of the research interview, eight years have passed since he first learned, back in 1985, that he has HIV. (Remember: unlike the reinforcement pattern, where crucial elements of the old identity have been retrieved giving ground to a third stage, the invalidation pattern consists of just two stages, with the period *after* diagnosis extending to the present.) When asked to describe his life before the diagnosis of HIV, he recounts:

- «*What comes to my mind?*»
- «*Yes.*»
- «*A happy-go-lucky attitude.*»
- «*Happy-go-lucky?*»

- «*That's a vast notion, right. But what comes to my mind is mainly the, um, ability to face daily problems not in a way ... that is, without this reference to seropositivity. That means very – in a very relaxed way – powerful when facing life situations, difficulties, joys, sorrows, anything in a very – in a devil-may-care attitude. You see?*»
- «*Tell me more about it. Maybe you can tell me an episode to make me understand better.*»
- «*Well, being happy, perhaps having at times to face negative life situations, you know, but to take them in a matter-of-fact way and so to live as well as possible.*»
- «*That's the situation now?*»
- «*No, that's the situation before. Do you understand? That is, not to be afraid of difficulties and, for better or worse, if one has to struggle to live, struggle, because it makes part of life. You see? Devil-may-care in this sense of not letting oneself get tangled up heavily in one's daily problems.*»
- «*And now?*»
- «*Now everything seems very difficult to me, even a small problem.*»

Interestingly, Giulio's distress is not related to any acute health crisis. He has not suffered any of the somatic afflictions that may strike people with HIV; his immunological situation is one of the best among all my respondents. Rather, social relations play an essential role. His decision to be tested was due to the suspicion that he may have caught the virus when having a sexual adventure outside his stable loving relationship. When his doubts were confirmed, he had already passed the virus over to his long-time lover. Rather than placing blame on Giulio or rejecting him, his partner said that he was ready to share this experience, if only their relationship would continue. It is hard to imagine a supportive reaction to such news. Yet Giulio felt so deeply distressed about, as he says, having “*destroyed*” his lover's life that he himself broke off the relationship.

At the time of the interview, Giulio blames himself much more intensely for having left his ex-lover than for having passed HIV to him. He also intensely blames himself for having quit a promising professional career because he was concerned that this job would impede compliance with the medical check-ups that are recommended to people with HIV. Finally, he blames himself for having lost some of his financial independence (having moved back to his parents' home for some time) and for earning his living with low-skill jobs now. These losses are examples of how Giulio has come to let himself «*get tangled up heavily in (his) daily problems*», rather than facing difficulties with ease and strength.

The culmination of Giulio's troubles, though, lies in the fact that he has never dared to disclose himself to a person with whom he thought possible to start a lasting loving relationship. As soon as an occasional sexual rela-

tion develops in a promising way, Giulio flees: his inability to disclose his serostatus is proportional to the degree of his emotional involvement. Telling his would-be partner that he has HIV would entail the risk that the relationship may end as a result of the other's rejection. Rather than running that risk, Giulio escapes, thus making sure himself that the relationship will come to an end. He cannot stand the idea of being rejected.

«Really, my world would collapse, because I, my way of life is closely related to emotional relations, in the sense that they are for me what gas may be for a car, or what electricity may be for a bulb.»

Giulio has entered a vicious circle: he cannot help reproducing patterns of behaviour that add to his distress, which is manifest as insomnia and hypertension. With every missed occasion at establishing a loving relationship, Giulio further fuels the fire of self-blame for *«not having known how to react to this thing energetically»*. He himself makes a connection between the destructive manner in which he has come to handle his emotional relations and the events back at the time of diagnosis. His incapability of disclosing himself to a lover toward whom he is developing a close emotional tie is due, as he says, to the fact *«that it has already happened to me»*.

On the face of it, this remark may refer to the fact of virus transmission. Yet, if this were the important problem, it would be hard to explain how Giulio can go on having sex with occasional partners without letting them know about his serostatus. I believe that the key to Giulio's current problem lies in his reaction to the diagnoses of HIV regarding himself and his friend, rather than those diagnoses as such. The point is that he did *“not succeed”* in handling that situation in a way which would have been compatible with his old self-image. On this interpretation, he would thus be avoiding disclosure to a would-be lover due to the fear that his partner may react similarly to the way in which he himself reacted when receiving the diagnosis.

Before, Giulio reports, he was capable of facing negative life situations in a powerful, matter-of-fact way, and hence able to enjoy life even in the presence of difficulties and sorrows. When confronted with the news of his and his boyfriend's positive serostatus, this way of conducting daily life *«did not withstand»*, as he says further on in the interview. Faced with the news of diagnosis, which he associated with the prospect of imminent death, Giulio felt *«in an offside position in the game of life, you see? Offside in constructing, in making yourself a future»*. The crucial difference between life with and without HIV, he repeatedly asserts, regards *«the way in which one lives, and the way in which one poses oneself relative to the problems of daily life»*. It is essentially in this sense that Giulio hopes for a return to *«normality»* as a result of

future breakthroughs in antiviral therapies (which he expects confidently). This return to normality does not mean life expectancy, but rather *«the way in which one poses oneself relative to the problems of daily life»*. At the time of interview, he asserts, his most intense distress stems from the thought that he has irretrievably lost eight years out of the most intense period of a person's life. For eight years in the third decade of his life, normally – in Giulio's view – a period in which people pursue their ambitions with zeal, he has felt to be in an *«offside position»*: *«I have become very timid, much closed, very introverted»*.

At the time of the interview, Giulio was wondering whether the lack of strength, which had been manifest in his conduct over the past eight years, reflects his true character. At times, he thinks that his tendency to blame his poor quality of life on HIV may just be an excuse for his own failings: *«because, fundamentally, in terms of my character, I may (have been) much more similar to how I am now when I was 20 years old»*. Even before diagnosis, he may already have been far less brave and outgoing than he now likes to think. After having made this remark, Giulio says:

«But I say to myself: 'sure. But then, fundamentally, the way I am, as a person I don't like myself.' I don't like myself that way, you see. Whether I have been conditioned by seropositivity, or else I am really like that, it's really bad, you see, because I don't like myself as a person that way (...). But anyway, no, I think that I am influenced a lot by this [i.e. HIV positive serostatus]. I think that if (...) some product [some medical drug] should come up which would make me turn alive again, I don't know, I have eight years of my life – lost, basically. I mean, it's like turning back eight years, you see. Because I feel it, I feel it, within my true personality is repressed.»

How different this assessment is from Francesco's matter-of-fact observation that there was *«a turning point»* in his life! Although for the better part of a decade, Giulio has not acted the way he would like himself to act, he glorifies that *other way* as the adequate expression of his *«true personality»*.

«You know, in a sense this thing, you see, it's odd ... maybe it's stupid to say so and stupid to think so, but to have found myself in this very particular, very difficult situation has enriched me incredibly. It has given me the possibility of being so present within myself, so deep with myself, you see, to dig so much within me – yes, it has enriched me a lot (...) And indeed it's very odd, finding a positive aspect, you know, in this whole thing. But, given that I cannot help living this reality, and given that in some way I have arrived inadvertently at reading myself so internally, analysing myself so profoundly, because the reason which has led me to be like this is not a fact of joy, but a fact of pain – but, all told, the result is the same: getting to listen to oneself, know oneself, understand oneself, read oneself as best as possible.»

The interpretation of HIV's lasting effect on the development of the self in terms of improved self-knowledge is not limited to representatives of the invalidation pattern; among my interviewees, it is also found with representatives of the reinforcement, continuity and void patterns. The specific manner in which such self-knowledge was obtained or aspired to changes from one pattern of biographical self-construction to another. For example, in the case of the continuity pattern, there is a perception of a continuous development toward better self-cognition, while in the void pattern, the individual is struck by the *lack* of adequate knowledge of her or his personal qualities. However, there is a common denominator: the "true" self is supposed to exist independently of the events or experiences by means of which the individual has come to "read" it, as it were. The self is conceptualised as a pre-established text that just needs to be deciphered properly.

Conclusion

Any observation that an individual may make regarding his or her personal qualities is, by definition, self-cognitive. This is true even of the statement "I have changed". That said, we might distinguish two fundamentally different ways in which such observations can be made. The distinction is subtle: it regards the relationship between self-cognition and self-transformation, rather than just juxtaposing the two. On one hand, the self may be conceived as having been decisively shaped by a specific event or experience. On the other hand, the individual may be convinced that his or her basic personal qualities have developed independently of any particular event or experience. In the latter case, any specific circumstances that have altered one's self-definition are conceived as revealing aspects of the self which were present already, but had previously gone unnoticed or had not properly unfolded as yet. The statement "I have changed" (as a result of a given event) is a typical example of the first sort of self-reflections; the statement "I discovered myself" (as a result of a given event) is a typical example of the second approach.

Both types of self-reflection differ markedly with a view to the status of the experience in question. Whenever self-construction proceeds in terms of enhanced self-knowledge, that experience is not conceived to have altered the self substantially. It is thought to have made a difference only with

respect to the degree and speed of self-cognition. In contrast, self-construction in terms of transformation proper allows for the idea that, in the absence of that experience, the affected individual's sense of identity would now be largely different.

Similarly, the two approaches also differ with a view to that elusive object of observation, the self. As I have just said, self-construction in terms of self-transformation implies that the affected individual's present sense of identity is the result of particular circumstances. It follows from an event or experience that made a real difference. In retrospect, it is clear that this event may or may not have happened. The individual is aware that her or his present self has come about in reaction to circumstances, which were not necessary as such – they may as well have been different. Therefore, if that event had not happened, the individual's sense of self would now be different. The self's development is conceived as hinging on contingent events in the individual's environment. In contrast, self-construction in terms of self-knowledge presupposes that the self itself defines the manner in which any possible transformation of self occurs. Particular life-events are thought to contribute, to a greater or lesser extent, to the revelation of personal qualities that are assumed to have existed anyway. Hence, the second type of self-reflection can be termed "self-actualisation".

As I have noted above, both self-actualisation and self-transformation have been observed among my interviewees. Yet, how should it be possible to derive, from interviews with a small group of people with HIV/AIDS, conclusions regarding contemporary Western subjectivity in general? In my interview material, there is a clear predominance of one of those two types, namely, self-actualisation, in terms both of the patterns of biographical self-construction and the total number of interviewees affected. However, in a qualitative piece of research such as this, numerical relations are not a sufficient basis for generalisations. Indeed, any generalisations that may be established because of this research are of a theoretical nature; they do not entail assumptions as to the empirical distribution of the two (i.e., self-actualisation *versus* self-transformation) in a given population.

In this sense, I would like to suggest that an interesting conclusion regarding the state of Western subjectivity can indeed be derived from this research simply by considering a basic quality of the empirical reality on which I have focused. As I have stressed earlier, the experience of HIV/AIDS is typically marked by the combination of biographical disruption,

on one hand, and lasting awareness of finitude, on the other. In retrospect, people with HIV have to take the effects of the event of diagnosis for their present sense of self into account. The very fact that contemporary Western individuals may establish that retrospective assessment in terms of self-actualisation is, I believe, highly remarkable. This is especially true for people belonging to the *invalidation*, *reinforcement* or *switch* patterns, for which the diagnosis of HIV (or related events) triggered a massive change in their self-definition. When interpreting as catalyst of improved self-knowledge a highly disruptive event that may *not* have happened (namely, the diagnosis of HIV and its consequences), my interviewees express the need for an objective principle of order in relation to which they may form their selves.

In traditional societies, people used to turn to such a presumably objective principle of order as a guide for conduct – especially (remember the example of the Stoics) in conditions of heightened awareness of mortality. Contemporary Western society is historically distinct from any other known type of society in that there is no longer an external principle of order whose objectivity can be assumed as indisputable. In its absence, the modern Western individual has to turn to the self as a guide to conduct. Personal qualities have become the dominant source of self-definition. The centre of gravity of the process of self-definition has turned to the individual's own life. As Georg Simmel has put it,

«After the individual had been liberated in principle from the rusty chains of guild, hereditary status, and church, the quest for independence continued to the point where individuals who had been rendered independent in this way wanted also to distinguish themselves from one another. What mattered now was no longer that one was a free individual as such, but that one was a particular and irreplaceable individual. (...) (Throughout) the modern era, the quest of the individual is for his self, for a fixed and unambiguous point of reference. He needs such a fixed point more and more urgently in view of the unprecedented expansion of theoretical and practical perspectives and the complication of life, and the related fact that he can no longer find it anywhere outside himself.» (Simmel 1984: 216/1971: 222f).

Historically, the shift toward self-construction by reference to distinctive personal qualities is a product of «one of the cornerstones of modern culture» (Taylor 1989: 376), namely expressivism. First articulated by the Romantics in the late 18th century, expressivism sustains the idea that we can and shall «find the truth within us» (Taylor 1989: 368). This idea contains a fundamental ambiguity between *making manifest* a truth that is ready to be revealed, on one hand, and *creating* this particular self-cognition as distinguished from other possible definitions of self, on the other. On one

hand, the “truth within us” is the object of research and discovery; it has to be articulated and actualised. On the other, the very articulation of that “truth” entails a definition, creation, or even invention.

Thus, the tension between contingent events and the premise of a continuous and coherent self is a basic feature of experience in contemporary Western society. Consequently, the juxtaposition of the classical modern and the post-modern self can be related to my distinction between two ways which the ambivalent relationship of *making manifest* and *making* may assume. The distinction between self-actualisation and self-transformation is a conceptually more elaborate re-formulation of the distinction between a classical modern self and a post-modern self. As I have explained earlier, both types differ most markedly with a view to the individual’s awareness of *being formed*.

I suggest that this difference is crucial. When an individual interprets her or his present sense of self as having been *revealed* by an event which may as well not have happened, the personal qualities which define that sense of self are singled out as fundamental. They are believed to exist independently of that event and prior to any particular event. A “don’t touch me”-status is attributed to them: the self-definitions are considered to be a necessary condition of experience, rather than a result of life-events. In short, these self-definitions are treated as an objective principle of order. For self-actualisation, as distinguished from self-transformation, the individual’s present self-construction assumes the position which, in pre-modern times, was held by supposedly objective, external principles of order, such as the Cosmos. Self-actualisation treats one particular self-definition, or set of definitions, as indisputable.

To conclude, limiting ourselves to the first of the two ways in which the HIV/AIDS pandemic potentially “touches upon” social reality, this condition highlights the tendency of contemporary Western individuals to pursue, in their biographical self-construction, a stability and coherence which their lives and biographies make impossible to attain⁽⁸⁾. According to my line of interpretation, the contemporary Western self continues to be more deeply intrigued by the pursuit of stability and coherence than any contributor to the current sociological debate on the self has realised. Rather than following the social environment’s trend toward ever increasing flexibility, contemporary Western individuals seem inclined to turn specific self-definitions into objects of devotion – despite clear evidence, in their own lives, that the self’s development is closely tied to contingent circumstances.

Notes

⁽¹⁾ Eleven of my respondents are likely to have been infected via sex among men (three of these men also injected drugs at some point), whereas six (two men and four women) were doubtlessly infected by sharing needles in the context of intravenous drug-use. One man was infected by blood-products for the treatment of hemophilia, and three women caught the virus when having heterosexual relations with partners whose past drug-use habit (two cases) or whose infection with HIV due to blood-products (one case) was not known to them at the time. Fourteen of my interviewees are thus men, seven are women.

⁽²⁾ The estimated time of infection ranges from one year and a half to eleven years and a half before the time of interview. With one exception, respondents did not suffer from serious physical constraints due to ill health at the time of interview (although the state of health of a further four interviewees was precarious due to an advanced state of disease progression). At the time of interview, about one third of my respondents qualified for classification as a "person with AIDS".

⁽³⁾ See Rinken (2000: 56 ff.) for a detailed review of the various analytical elements of the diagnosis in terms of their contribution to biographical disruption.

⁽⁴⁾ Charles Taylor's *Sources of the Self* (1989) offers an influential historical account of the modern self's emergence; see especially chapter 21 (Taylor 1989: 368ff.) on the «expressivist turn», i.e. the emergence of self-definition in terms of personal qualities.

⁽⁵⁾ For other relevant contributions, see Gergen (1991), Zurcher (1977) and Lifton (1993) for the "post-modern" and Hewitt (1989), Leinberger/Tucker (1991) and Schimank (1985; 1988) for the "late-modern" approach.

⁽⁶⁾ There is no necessary relation between any of the two types of biographical self-construction with a view to the overall effects of the experience of HIV that I am going to discuss now (i.e., self-actualization and self-transformation), on one hand, and the patterns or modes of biographical self-construction that I discussed earlier (invalidation, reinforcement, switch, void and continuity), on the other.

⁽⁷⁾ For my quotations from the interview material, I shall use the following symbols. Three dots signal a pause, i.e. a temporary interruption of the flux of words. Three bracketed dots signal an omission in the context of just one particular answer given by the respective informant. Three bracketed backslashes indicate that I have composed one quotation from answers to several questions in order to obtain a concise statement on a specific topic without having to document lengthy passages of the interview. In these latter cases, I have always respected the principle of sequentiality: the elements of that composed quote follow each other in correspondence to the actual interview sequence. Square brackets are used when I have added editorial remarks to a quote in order to render it more comprehensible.

⁽⁸⁾ The contemporary Western self can thus be called the nihilist self – provided that the term "nihilism" is not understood as the advocacy of moral relativism (as a well-established but misled reading would have it). Rather, the concept refers to a fundamental long-term process in the history of the West, namely, the dissolution of any generally accepted, integrative and supposedly objective principle of order capable of shaping the individual's conduct and self-definition in all walks of life. «This is what Nietzsche calls nihilism, that men continue to pursue in their lives and intelligence what their intelligence and lives make impossible to attain» (Strong 1988: ix).

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