

Political and Social Sciences Department

After Diagnosis
HIV, the Prospect of Finitude,
and Biographical Self-Construction

SEBASTIAN RINKEN

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"After Diagnosis.

HIV, the prospect of finitude, and biographical self-construction"

by Sebastian Rinken

Abstract

How can individuals in contemporary Western societies constitute themselves as mortal beings? This question is addressed, in the following paper, on the basis of a series of interviews with Italian persons who have HIV or AIDS. Typically, at the time of diagnosis, the knowledge of having HIV was associated to the prospect of imminent death; this shock provoked the disruption of a particularly cherished aspect of the previously taken-for-granted self-definition. When looking back at their past in the research interview, most respondents had overcome the sense of emergency which had been triggered by the event of diagnosis; the thought of imminent death had turned into the lasting awareness of finitude. Given this double impact of the thought of mortality, how is it possible to reflect on one's life and self?

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Introduction

AIDS seems to be in the process of becoming a chronic disease. If the new triple drug therapies hold their promise, the character of AIDS as a terminal disease may come to belong to the past - at least for those rich or lucky enough both to obtain access to those drugs and to tolerate their often insidious side-effects.¹ If it should indeed be possible to eradicate the Human Immunodeficiency Virus from the body even at an advanced stage of disease progression, there would soon be hope of prolonged survival for people whose life-expectancy used until now to be measured in months, rather than years. Long-term survival of AIDS would turn from exception to rule.

This chronification of secondary infection with HIV, if it should indeed come true, echoes and reinforces the development of primary HIV-infection throughout the past 15 years. In the pandemic's early years, the diagnosis of HIV-positivity was prone to be conceived as a "death sentence" just as much as the diagnosis with AIDS proper - unless the affected individual was kept by specific background experiences from taking that association for granted. HIV's chronification has not, that is to say, been observed by scientists only. Those among the infected who were diagnosed at a time when the connection of HIV/AIDS to impending death was still dominant in social discourse, but who then turned out to live on far beyond their initial expectations, have made a direct experience of HIV's change of character. The close association of impending death to the news of HIV-positivity has actually tended to outlast the availability of medical evidence for an extended life-expectancy of the infected: for both technical and existential reasons, the perspective of the individuals concerned is likely to lag substantially behind the scientific state-of-the-art (compare e.g. Schemmann 1996: 129). This

¹ For a fairly comprehensive - and intelligible - summary of current biomedical research, compare *The Economist* of May 10, 1997: 87 ff.

pattern is apt to repeat itself: the image of death will probably continue to haunt many of those diagnosed with AIDS even at a time when, from a medical perspective, its potential qualification as a terminal condition has long become subject to observations regarding the tolerability and efficacy of therapeutic drugs.

The past chronification of HIV differs from the one now thought to be possible: the complete eradication of the virus from blood and tissue would deserve to be qualified as a cure. In contrast, the big change from the early 1980ies to the mid-1990ies lay with the average time-span expected to elapse from seroconversion to death: it has extended from just a few years to a dozen and more. Even while learning that death is not as imminent as had first been thought, an individual who lives on with HIV far beyond initial expectations is apt, until now, to think of his or her condition as ultimately terminal. Even after the shock of diagnosis is overcome, the individual has to face the thought of a life-expectancy much shorter than that of his or her age-group.

I shall like to stress that my emphasis on the character of HIV/AIDS as an ultimately fatal disease does not contain a deterministic dimension: I do not wish to reinforce the notion that any individual diagnosed with HIV or AIDS were prone to die of that condition. My remarks are second-order observations: the intense connection of HIV/AIDS to the problem of death is a historical fact. The very notion of "long-term survival" (as it has been used up to now) implies that the continuation of life with the virus beyond certain benchmarks happens against the odds. This points to the mental difficulty of overcoming the potentially paralyzing effects of the thought that one's death may be close; the achievement consists of making prolonged survival look like a real possibility. Long-term survivors do not deny they have a fatal disease - they just live with one. Under normal circumstances (in contemporary Western societies and with regard to the age-groups most affected by HIV, that is to say: against the background of a taken-for-granted life-expectancy of at least six decades), any reminder of the possibility

that one may die soon tends to be conceived as either highly terrifying or just unreal. In contrast, under the condition of intense association of one's immunological state with impending death, to think that one may as well live on constitutes a big achievement (compare Callen 1990). The appreciation of the future's uncertainty hinges on the sort of certainty against which it is set.

I do not intend to reinforce the notion that infection with HIV will inevitably lead to AIDS, and that AIDS will inevitably lead to death; I am not interested in mortality patterns in a statistical sense. I wish to better understand the experience of mortality as it is made by persons with HIV/AIDS. For all those who spontaneously associated their diagnosis to the thought of impending death, one crucial problem of living with HIV or AIDS consists of the management of that thought. Even after the first shock has faded, it is impossible to simply get back to the previous assumption of an open future. The individual has to establish a new relation to the problem of death: neither can survival to old age be again taken for granted, nor can death be continuously expected as imminent. Uncertainty about the future has to be accommodated with respect to the individual's life and self: the individual has to constitute him- or herself as a mortal being. The awareness of having to die *too soon* has to be rendered compatible with a meaningful conduct of life and a valued self-description.

Life with HIV and AIDS can hence be analyzed as a process of self-constitution as mortal, and the variety of ways in which individuals with HIV or AIDS construct their lives and selves can be observed with a view to the form which constitutes that variety's common denominator. This terminology, and the corresponding will to knowledge, are inspired by the last period of Foucault's work, which was devoted to the exploration of historically specific patterns of subjectivity with regard to the experience of sexuality (Foucault 1984, 1984a). My Ph.D. research (Rinken 1996), on which the following considerations rely, aims at exploring the experience of mortality along similar lines. To be sure: there is

no comparison between the scope and depth of Foucault's scholarly enterprise and the modest results I am able to present. Still, the perspective from which I study HIV/AIDS owes a lot to Foucault: from a series of autobiographical narratives, I try to discern the form of the self-constructions of individuals who have become intensely aware of their finitude as a result of the diagnosis of HIV or AIDS. Which role does the thought of mortality play in those constructs? How are the effects of the thought of death on life and self taken account of?

Self-constitution as mortal

As is well known, Foucault's inquiry into the experience of sexuality led him way back into Greek and Roman history. This is because the specificity of our (modern Western) pattern of making a particular experience can be observed clearly only against the background of historically or culturally distinct such patterns. For any study which, like mine, relies primarily on empirical material from a contemporary Western society, this means that assumptions as to its specificity can be introduced by reference to literature only. Why bother, then, about the historical and cultural dimension at all? This question can not be answered without going to some extent into the heart of the matter. I shall make my point by referring (in a daringly sketchy way) to two sorts of literature: the history and sociology of death and dying, on one hand, and the history of the relation between individual and society, on the other.

Has death in modern society turned into a taboo? As is increasingly recognized (compare Walter 1991, Mellor 1993), the growing body of literature which sustains that assumption is self-defeating in that a topic about which so much publishing is done can hardly be termed a taboo. But that literature is after something: more or less consciously, it aims at exploring modern attitudes and practices towards death in their historical (and cultural) specificity. Some basic observations, such as the absence or poverty of secular funeral- and mourning rituals or the institutional appropriation of death and dying, can hardly be contested. Yet, at the heart of the taboo-debate lies an observation which goes well beyond the lack of shared practices and the separation of death from the everyday world. At bottom, the idea is that modern individuals be more scared by death than their ancestors.

I have cautiously written "the idea" - because its validation is an awkward enterprise. Yet, if one takes it that the work of scholars such as Philippe Ariès (1977) points to some real development, and if one does not wish to explain the

modern individual's specific attitude towards death simply as a complement of institutional developments (by arguing that the alleged "taboo" be simply a result of increased longevity, i.e. the symptom of a lack of concern), there are two possible explanations for modernity's particular distance from death: its reason can either lie with the material idea of death, or else with particular characteristics of modern individuality. It is easy to see that the first of those options can be discarded: just think of the terrifying effect which the thought of death ought to have in the Middle Ages, when its material image consisted not just of the end of life, but potentially (and who could be sure not to have sinned?) of exposure to the Purgatory. This is to say that, on sober comparison, the secular idea of death does not seem to be the most dreadful (apart from the fact that observations on the denial of death have also been made in countries, such as the U.S., where the secular vision of death is, put cautiously, not uncontested). Yet the average Medieval sinner had tools for handling that dread which rendered it manageable - a sort of tools which, in modernity, seems to have come to lack. Indeed, the *memento mori* was a widespread practice then - to the extent that it is now widely associated with Christian faith.

Erroneously, as the history of philosophy shows: there were a number of philosophical schools which advocated the thought of one's own death as a technique of self (Hadot 1981). Those schools, though, could rely on the assumption that there was a definite standard of conduct and self-organization *external* to the self, such as the Cosmos. This is to say, when confronted intensely with the thought of their own finitude, people were not threatened by meaninglessness. Similarly, when dreaded by the thought of the Purgatory, Medieval Christians knew they had to step up compliance with the moral code (Ariès 1977; Delumeau 1978). In contrast, for modern individuals, a definite standard is not available any longer: any affiliation to sources of shared meaning, including religious faith, has become a matter of choice.

This leads to the second body of literature on which I would like to comment briefly: the history of the relationship between self and society. Modern society's lack of shared, definite standards does not regard patterns of conduct only: it extends to the way in which individuals define their selves. There are no external reference-points any more which would unambiguously locate the self: the definition of identity has become, in modernity, an explicitly individual problem. As Luhmann notes, the substitution of the traditional hierarchical order of society by the differentiation of self-referential functional subsystems has brought about the impossibility for the individual to establish a viable self-description with regard to a fixed social position; rather, the self is now constructed by reference to its supposed singularity (Luhmann 1984: 354 ff., 1989: 149 ff.). Similarly (albeit writing from entirely different quarters), Taylor has stressed modernity's historical distinctiveness in that the individual is held to define her or his ultimate horizon by reference to personal attributes, rather than to qualities of class, rank, or status (Taylor 1989: esp. 368 ff.). The singularity of the individual is not an objective quality, though - it is the result of an ongoing process of assessment. In modernity, as Giddens argues, self-identity has turned into 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*" (1991: 53).

This is not to say, of course, that people living in traditional societies would be incapable of reflecting on their own lives - nor do I wish to imply that a modern individual's self-reflection takes place in a social vacuum. Yet, unless the literature to which I have referred is all misled, only in modernity has the individual's own lifetime turned into the central basis for defining identity; correspondingly, only in modernity has the individual turned expressly into the chief actor of that process of definition. Much more than the assessment of definitions imputed on the self by others in a given moment, the construction of one's self with a view to the past, future, and present is the individual's uttermost personal business. The

foremost audience for a biographical self-construction is the individual her- or himself: especially with regard to lifetime issues, one's *inner* dialogue enjoys a privileged position (compare Mead 1934: 139; Rinken 1996: 305 ff.).

Now, it is easy to follow Mellor (1993) in his assertion, elaborated by reference to Giddens (1991), that the modern individual's historically distinctive reliance on biographical self-construction, on one hand, be related to the specifically modern problem with death, on the other. But is it true, as Mellor (1993: 18) writes, that the constitutive reflexivity of the modern individual can not possibly help "deal with the phenomenon of death, since this is a universal parameter within which reflexivity occurs, rather than an object to which reflexivity can be convincingly applied"? In the context of Mellor's discussion, this assertion serves as a stepping-stone towards the claim that the problem of death needs to be brought back to the community - i.e., to the level of shared social practices. For anybody not aprioristically committed to that goal, it may be worthwhile to consider the relation between modern individuality and the thought of mortality more in detail. Granted that we can never conclusively know what comes after death, the modern individual's reflexivity may still be of help in dealing with the awareness of finitude. The problem would hence lie with specific ways in which self-reflections are performed, rather than with biographical reflexivity as such; in particular, it can be suspected to lie with a specific sort of relations between past, present, and future.

Future? To think of one's death means to think of the future's absence, or else of one's own future's absence. Events which trigger the intense awareness of one's own finitude do, by definition, often imply that there is not much time left ahead. As far as medical diagnoses are concerned, such awareness will usually be provoked by a "terminal" diagnosis, which in general implies that the life-expectancy of the individual be estimated in terms of months or, at best, a strictly limited number of years. Typically, this was also the case with individuals diagnosed as having HIV or AIDS throughout the pandemic's first decade: death was perceived

as imminent; there was to be no future. All those who have lived on for an extended period of time after that diagnosis, though, have had occasion to observe that the thought of death is not necessarily incompatible with future life: after all, life has continued despite the ongoing (albeit not always manifest) awareness that it may soon draw to its 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 performed at a given time can be sustained as valid only if it is compatible with the possibility of dying rather soon - otherwise, any reminder of one's finitude may cause depressive crises. Second, that self-construction has to accommodate the effects of the event which first provoked the invasion of the thought of death into consciousness. 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 one hand, and past disruption (if diagnosis was indeed perceived as a disruptive event), on the other.

Method and data

In the Spring of 1993, I conducted semi-structured interviews with 21 Italian individuals with HIV or AIDS. With the exception of two personal acquaintances, contact to interviewees was established via associations of or for the HIV-positive. I did not try to direct the composition of my group of interviewees except for the inclusion of as broad a range of epidemiological features as possible. As a result, eleven of my respondents are likely to have been infected via sex among men (three of these men also made use of intravenous drugs at some point), six (two men and four women) were doubtlessly infected by shared needles; three women were infected by straight sex with partners whose past drug-use habit (two cases) or whose infection with HIV due to blood-products (one case) was unknown; finally, I also interviewed the ex-fiancée of this last woman, who had caught the virus from products for the treatment of haemophilia (these two latter cases were personal acquaintances). Fourteen of my interviewees are thus men, seven are women; age at diagnosis ranges from 19 to 48 years (in two-thirds of cases, from 19 to 29 years), and time of diagnosis ranges from 1983/4 to 1992 (with twelve cases diagnosed in 1987 or earlier).

Thus, some respondents had a long experience of life with the virus; others had been diagnosed as little as one year before interview. Yet due to the particularly slow move of Italian public awareness campaigns from advertisements emphasizing the risks of transmission and the need to avoid it, on one hand, toward a message underlining the chronic character of the disease and the need for HIV-positives and -negatives to share daily life, on the other, all my interviewees were diagnosed under the circumstance of a primarily "terroristic" social image of their condition²: the association of imminent death imposed itself spontaneously on

² Compare Berridge/Strong (1992) for a periodization of AIDS-policy and Moss (1990) for an overview on the Italian public's reaction to the epidemic's emergence.

close to all of them. From the indications given by my interviewees, one can infer that more than two thirds had been infected with HIV at least five years before the interview (with a range from one and a half years to eleven years and a half); with one exception, respondents did not suffer from serious physical constraints due to ill health at time of interview (although a further four were in a sufficiently advanced state of disease progression for their state of health to be termed precarious). About one third of my respondents have to be classified as "persons with AIDS" according to current epidemiological rules.

All of the interviews began the same way. I mentioned that my questions were going to refer to daily life with the virus, to then say that, before moving on to that argument, I wanted to jump back into the past and learn something about life before HIV-positivity. I asked each respondent to volunteer whatever came to her or his mind at that regard. My initial question thus implied a relevant difference between past and present - an implication which was always grasped by my informants, albeit not necessarily in an affirmative way. This is to say, while asking for an evaluation (rather than matter-of-fact information), I did not force the distinction between past and present upon my respondents: who did not think that it fit his or her case was free to say so, and indeed did (as we will see below). My initial question provided a good start both in establishing the lifetime perspective as the interview's reflective dimension, and (given that this perspective was not perceived as far-fetched, but proved pertinent to my respondents' life with the virus even in those cases in which diagnosis had not constituted a watershed) in establishing myself as a person sufficiently well-acquainted with the problem of HIV/AIDS to be told delicate details about that experience. Throughout the rest of the interview, I tried to strike a balance between follow-ups on information already obtained, on one hand, and my predefined areas of interests (in particular, the way in which the thought of death had been handled both mentally and socially), on the other. Ideally, this simply meant asking for further information on points touched upon in the course of previous statements.

My prompt situated the interview immediately at the level of reflection. The initial question implied the, if rudimentary, theory that knowledge of one's own HIV-positivity may make a difference to the person affected - indeed that it may literally affect that person. Banal as that assumption may sound, to start the interview with this question constituted a methodological choice. This procedure runs counter to the current wisdom of the "narrative interview" school, namely that the interviewer has to abstain from requests for evaluations until matter-of-fact information has exhaustively been provided (Schütze 1984, Rosenthal 1995). General doubts as to basic assumptions of that approach (in particular, the presupposition of a close correspondence between the layers of a narration established with a minimum of external interference, on one hand, and the narrated events as they were experienced, on the other) become all the more pervasive with regard to an experience such as HIV-positivity. Rather than cherishing the illusion that the interviewee's narrative may simply reproduce experience "as it really was", my approach emphasizes the character of any observation made in the interview as an action taken at that very time (compare Mead 1932). While talking about their lives and selves, my respondents did not just reproduce past experience: they reflected upon their past in the light of the present, and about both present and past in the light of an uncertain future. This is not to say that I think respondents invented their stories out of the blue. I believe that the selectivity and structure of an autobiographical report be a result of the narrator's self-definition at the time of narrating - and that this self-definition is in turn determined crucially by outstanding life-events. The narrator's sense of identity, on one hand, and her or his life-story, on the other, mutually constitute one another. Any inference as to the "reality" of past events is thus a second-order interpretation: it is the result of the social scientist's effort at understanding the informant's construction of the past in its relation to the present. On the assumption that a traumatic event leaves important traces on the self, and that the relationship between such a past event and the narrator's present identity is thus evoked pre-

cisely by a question regarding the difference made by that event, my initial prompt can be appreciated as conducive to valuable and valid results. It may be worth noting that the main theorist of the German narrative school has explicitly acknowledged, shortly before turning the distinction between narration and evaluation into a methodological doctrine, that any retrospective account of one's life inevitably comprises a critical, reflexive, hence an evaluative dimension (Schütze 1976: 20). Specifically with regard to traumatic experiences, Schütze's pupil Rosenthal has recently stressed that the expectation of a close correspondence between the layers of lived experience and the layers of an unrestrained narration of one's life will not be fulfilled (Rosenthal 1995: 120; 130). My interview technique builds on such insights, rather than the current orthodoxy.

The interview transcripts were interpreted in two steps, corresponding to the two main phases of work with ideal types in historical research as outlined by Max Weber (1904: 184 ff.; compare Schelting 1922: 684), namely their establishment and subsequent use; the idea of applying this method to autobiographical narratives I owe to Gerhardt (1985). On the basis of all the interview material, an ideal-type hypothesis as to the crucial challenge of Living with HIV or AIDS was established; this conceptualization regards the consequences of the diagnosis of HIV for the affected individuals pre-established self-description. Subsequently, this ideal-type was used as a tool for the detailed interpretation of selected single interviews. In what is generally referred to as a hermeneutic circle, the result of the in-depth interpretation of single cases has come to in turn reinforce and specify the original interpretative hypothesis. I would like to stress that the ideal-type generated in the first step of interpretation has the character of a conceptual yardstick - it is not a self-fulfilling prophecy. While rather closely grasping the characteristics of some cases in terms of a hypothesis-forming model, in others it just serves as a means of contrast. This clearly means that the results of my in-depth case interpretations are not independent of the kind of conceptual yardstick with which they were established. While that yardstick was

derived from the empirical material itself, it then came in turn to be applied to the generation of insights regarding that very material. Rather than claiming that no other second-order-observations than mine would have been possible on the basis of the given empirical material, I feel it is a matter of intellectual honesty to lay bare the character of my (just as any other) interpretation as partly contingent on the observer's focus of interest: differently to what the German narrative school tends to believe, the second-order-observer is not just the voice of the material as it speaks to us. For my procedure, it is thus essential to establish the non-arbitrary character of the basic interpretative hypothesis beyond reasonable doubt.

Diagnosis of HIV and the "diagnosis of the self"

As a result of the pioneering works of Blaxter (1976), Bury (1982), Charmaz (1983, 1987, 1991) and Strauss (Strauss et al. 1984/1975; Corbin/Strauss 1987), the assumption that the onset of chronic illness is experienced as a biographical disruption has come to be widely recognized in recent years. Beyond practical considerations, medical sociology now routinely conceives the onset of chronic illness as an "assault on self-hood" (Bury 1991: 456): the constraints imposed by illness are not limited to the individual's range of activities, but affect taken-for-granted images of self. Having previously been conceived as capable of performing tasks which are now beyond reach, the self is downgraded (and possibly, during periods of remission, again upgraded) in response to the level of physical performance and, consequently, the state of social relations (Charmaz 1983, 1987). The integration of the different periods of life which are marked by one or several "turning points" (Charmaz 1991) related to the experience of illness transforms reflections on one's course of life into "biographical work" (Corbin/Strauss 1987): the continuity and unity of the self can not be taken for granted any longer. Rather, the individual may seek to actively constitute bridges between old and new by means of a variety of techniques such as contextualizing or biographical recasting.

The basic assumption of all this literature is that changes of the self-image reflect actual or, eventually, anticipated changes of the physical self: losses of self are thought to be triggered by the manifestation and/or diagnostic identification of symptoms ("body failure", as Corbin/Strauss call it). As far as somatic illness is concerned, that assumption seems perfectly adequate. Yet, with respect to the diagnosis of HIV (and, to some extent, of AIDS), it tends to veil an important aspect of the repercussions which such a diagnosis may have on the self. The effects of diagnosis with a terminal condition (with a condition, that is, understood to be terminal) are not limited to complements of somatic symptoms. When

suddenly facing imminent death, the self may be shattered in ways unrelated to any specific constraint imposed by physical disfunctionality. Diagnosis with HIV is prone to trigger the anticipation not of partial, but of total body failure. What are its consequences for the self?

Research on HIV/AIDS is just beginning to explore this dimension. Throughout the first decade of the pandemic, the social sciences have largely focused on the potential moral connotations of the main means of transmission (compare Pollak et al. 1992); biographical disruption and biographical work have thus first been studied in terms of the individual's sense of belonging to a group of peers, as defined by the practices which had caused virus transmission (Carricaburu/Pierret 1995). Most of the researchers who were concerned specifically with the association of this condition to the problem of death have either just classified reactions to diagnosis according to psychiatric categories (compare Kalichman/Sikkema 1994 for a literature review), or narrowly focused on the process of physical decline and dying proper (generally building on the approach first introduced by Kübler-Ross 1970). Only few studies have as yet looked at the diagnosis of HIV as a traumatic event affecting everyday assumptions about oneself and the world independently of the manifestation of symptoms or the association of HIV with potentially negative moral evaluations of conduct. Weitz' important monograph (1991) places the accent on moral stigma and physical debilitation rather than on the disruptive potential of the thought of death; the early impulses by Sandstrom (1990) and Siegel/Krauss (1991) have found little echo. While Schwartzberg (1993) and Nédélec (1994) provide interesting preliminary analyses of ways in which meaning can be ascribed to a life marked by diagnosis, Shea (1995) suggests to analyze the threat of meaninglessness incurred by diagnosis with a view to the plurality of social constructions of HIV/AIDS. According to Shea, *all* of the individual's previous sense of identity is rendered highly precarious by the news of diagnosis; he speaks of a situation of anomie. In contrast, Davies (1997) concentrates specifically on disruptive effects regarding assump-

tions about the future. But is not the future dimension of conduct and self intimately related to the individual's pre-established sense of identity? And is not one's self composed of a variety of aspects which may not all be equally affected by the news that one's death be close?

As Corbin and Strauss (1987: 249) have put it with a view to all kinds of body failure, "when a chronic illness comes crashing into someone's life (...), the who I was in the past and the who hoped to be in the future, in whole or in part, are rendered discontinuous with the me of the present". This statement illustrates well both the general line of thought which has come to be widely accepted in medical sociology (namely, that the onset of chronic illness may disrupt one's sense of identity) and the two crucial issues on which I would like to extend now with regard to the specific nature of the diagnosis of HIV-positivity (and of AIDS, if its diagnosis is made on the basis of a T-4 cell count below the marker level of 200 per milliliter blood, rather than the manifestation of an opportunistic infection or cancer). HIV is specific as against chronic illness in general in that it is not, during its asymptomatic stage, an illness proper: rather, it constitutes the announcement of a future illness. At the same time, HIV is bound to be associated with the prospect of premature death. This double specificity raises two crucial issues: firstly, the relation between past and future among the loss of self which is suffered, and secondly, the nature of the affected self as either unitary or multiple. In thinking about these issues, I adopt the conceptualization of consciousness as a self-reproductive system as developed by the German sociologist Niklas Luhmann (1984: 354 ff.; 1987), which I blend with basic insights of American social psychology (Fiske/Taylor 1991; Markus 1977; Markus/Nurius 1986).³

³ See Rinken 1996: 108 ff. and, for a more detailed formulation specifically in terms of the theory of self-reproductive systems, Rinken 1997; in a forthcoming article, I will

In a nutshell, the theory of self-reproductive systems presupposes that consciousness, like any other system, operates recursively by reference to its own elements, rather than by direct access to the environment in terms of input and output. That is not to say that self-reproductive (or autopoietic) systems would exist in a vacuum; yet all of the system's environment, including news and events, is observed by the system on its own terms. Such observations have binary character: consciousness operates by distinguishing, i.e. by indicating *this* rather than a contrasting *that*. In principle, this process goes on and on: any observation can in turn be observed by its successors. It is thus possible, as a subsequent observation, to switch to the other side of a distinction that was previously used, or else to observe a distinction's unity. It is also possible to make observations on the operating system itself in its quality as a system. Yet it is important to note that, contrary to observations in general, self-descriptions of the system are by definition not bi-stable. While consciousness can switch without any difficulty from the expected observation, say, that the sky be blue, to the observation that it is indeed covered by threatening clouds, it is not possible to simply dump pre-established observations regarding the system's own distinctiveness as against its environment, and replace them with their opposites. The more important the pre-established view of self was, the less possible will such a replacement be. The autopoiesis of consciousness may thus run into trouble when self-descriptions of the system are suddenly observed as defied.

This is bound to happen at time of diagnosis. The result of the serological test is likely to be interpreted in terms of a dichotomy: "negative" is associated to future life, "positive" to the threat of death. This contrast regards not just the system's future, but by the same token its present self-description as a system which

present my conceptualization in close discussion of the State-of-Art of medical sociology and social psychology.

will continue to operate in the future. Consciousness knows that the continuation of its operations relies on a living body. With a view to this crucial self-description, the system oscillates between the two poles of a binary distinction. The prospect of imminent death can not be accepted as a description of self - yet the previously unshattered trust into an open future can not simply be resumed.

What is going to happen at this point? Given the difficulties it encounters when tackling the news of positivity, consciousness may go on by switching to other topics, i.e. by letting itself distract from that news. Yet due to its relevance, the thought of imminent death is bound to return. I hence suppose that, sooner rather than later, the system's self-description will be affected in a second way. The news of positivity is conceived as a threat to life; it hence contradicts the pre-established view of self as striving towards an open future. It thus seems plausible to assume that that news will, in a second step, be referred to a specific way in which the affected individual used to strive towards the future. Rather than to the generic quality of being alive, the threat of death is connected to a distinctive quality of the individual, namely to a definition of self which used to constitute, prior to diagnosis, a relevant element of her or his sense of identity.

This specification of the aspect of self which is particularly threatened by death is apt to make matters worse. Schematically, there are two possibilities: either this old self-definition is maintained even in the presence of the threat of death, or else it is perceived as invalidated by that threat. Given that the condition on which that old self-definition had relied, namely the taken-for-granted nature of an open future, has been denied by the news of diagnosis, I think it is fair to assert that the second of those alternatives is more likely. This is what I suggest to call the "diagnosis of the self": a specific aspect of self is singled out from a range of possible candidates (from the working self, as social psychology has it) as threatened by imminent death. A specific way in which the individual used to think about his or her self suffers a sudden loss of validity, thus triggering the

crisis of an established way of conceiving the distinctiveness of the system as against its environment, i.e. its identity.

The diagnosis of HIV thus works as a "dispositive of truth" (Hahn 1994) - albeit in a way which is not necessarily related to the two categories usually used by social scientists to account of that event. The "diagnosed" aspect of self may relate to the most prominent means of virus-transmission, and hence to the social groups distinguished by the respective practices - yet this connection is neither automatic nor standardized. Many among the infected were fully aware, prior to getting tested, that they had engaged in sex between men or into intravenous drug-use - and in the case of many, those practices were fully accepted by the relevant social environment. This, in other words, is not the news they conceive when learning to be HIV-positive. Rather than the fact of having used drugs or of having had sex with other men, I thus suppose that it will often be the way in which the individual used to move in the respective social environment that plays a part in the determination of the aspect of self which is particularly affected. I certainly do not wish to obscure the possibility that the disruptive potential of diagnosis may in some cases be enhanced, and in many more cases directed, by the fact that the moral mainstream does not approve of the practices by means of which most people in the industrialized world have become infected with HIV. But it does not need moral concerns to turn knowledge of one's positivity into The Big News: the association of a sharply reduced life-expectancy will do. Similarly, I do evidently not mean to claim that the diagnosis of HIV (and, all the more so, of AIDS) may not, at the level of the self-definitions most affected by that news, be related to the onset of symptoms. Rather, I wish to highlight the fact that there is no necessary connection between such a diagnosis, on one hand, and the disruption of aspects of self related to specific bodily functions which are observed or expected to fail, on the other. While some people may have a sufficiently clear idea of this disease's potential manifestations to be scared right at time of diagnosis by the possible advent of a particular scourge even in the ab-

sence of manifest symptoms, this is not necessarily the case. Rather, the association of impending suffering and death may more broadly be understood as a threat to future life.

To summarize: on the basis of a first consideration of my interview material in the light of current theories regarding the procedural character of consciousness and the status of self-definitions as elements of that ongoing process, I believe that the sudden irruption of the concrete prospect of total body failure into one's mind is apt to provoke the disruption of a specific aspect of self, rather than of the totality of all the assumptions which one used to hold about oneself previously. The biographical work to be undertaken during one's life with the virus will thus specifically regard the aspect of self which, on mentally processing the news, has been singled out as specifically distinctive of one's own way of striving towards the future - which is to say: of one's past. Together with the future, one's past is perceived as lost; the very moment of being singled out as outstandingly relevant for one's recent past spells deep trouble for the respective aspect of self.

The above conceptualization of diagnosis accentuates some qualities of the diagnosis with HIV/AIDS, while de-emphasizing others. This is not to neglect the existence of those other qualities, or to project that conceptualization into my empirical material regardless of evidence. On the contrary, the ideal-type of "diagnosis of self" which I just sketched is the product of observations on the interview material; it constitutes an instrument for the generation of further, more specific empirical observations, rather than a final result. The crucial justification for the use of such a general interpretative construct is that it may open up insights otherwise precluded.

Types of biographical self-construction

How do people with HIV or AIDS construct their lives and selves? In the following, I will present the five distinct patterns of biographical self-construction which have emerged from the 21 interviews conducted for this inquiry. These patterns constitute analytical types in that they exhaustively cover the range of ways in which one may locate one's self with respect to a past marked by the knowledge of positivity.⁴ The typology is established with regard to the periodization of one's life relative to the diagnosis of HIV/AIDS. Is the implication of the interview's initial prompt, namely the distinction of subperiods of life *before* and *after* diagnosis, accepted? In other words, does diagnosis take on the role of a decisive biographical marker or turning point? If yes, how is the self at time of interview related to those two subperiods of life? And how are the effects of diagnosis on the self taken account of?

Much of the discussion of each pattern will concentrate on one exemplary case; in a second step, I will make observations regarding the background experiences which facilitate the manifestation of each particular pattern of self-construction. In focusing largely on one exemplary case, I am well aware that there is a tendency for readers to skip such discussions and move on directly to the more general conclusions. Any reader of this piece of writing is free to do so - at a price. The more general observations which I will make further on presuppose familiarity with the patterns of self-construction as previously presented. Like it or not, the best way of presenting such patterns is to discuss one exemplary case

⁴ The types presented here constitute the possible range of variations in terms of extremes; self-constructions somewhere mid-way between two of these types (such as the experience of an invalidating disruption in occasion of the diagnosis of AIDS years after an experience of continuity with regard to the original diagnosis of HIV) are not excluded.

in some detail. I shall furthermore like to stress that the selection of cases as exemplary was achieved by one simple criterion, namely the extreme character of the respective self-construction with regard to the interview prompt. In other words, the five cases which I will now present constitute the extreme poles of a field of options within which all of my other respondents, and supposedly (as I would dare to claim) all modern Western individuals living with HIV or AIDS, can be allocated.

One final remark: my criterion for selecting cases as exemplary entails a potential distortion which I would not know how to avoid, but which I would like to signal as such. As Charmaz (1991: 274) has noted, the "more articulate or expressive men and women made more apparent what remained implicit in others". In other words: while building on the reasonable assumption that observations and patterns voiced by particularly articulate informants be potentially pertinent not only to their personal case, my approach indubitably privileges individuals with good communicative skills. This means that there is an "expressiveness bias" - not just in this research but probably in any sociological study based on qualitative interviews for the simple reason that such research relies on the participants' words.

Invalidation

"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, eh, ability to face daily problems not in a way ...⁵ that is, without this reference

⁵ Three dots signal a break, i.e. a temporaneous interruption of the interviewee's flux of words; three bracketed dots stand for an editorial omission in the context of just one particular answer given by the respective informant, while three bracketed backslashes

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 manner. 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 see, but to take them in a matter-of-fact way, and hence 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 anything seems very difficult to me, even a small problem."*

This is the initial sequence⁶ of my interview with Giulio, who had been 23 years old at time of diagnosis. I have chosen to document this sequence in detail because, as a rule, each interviewee's reaction to the initial prompt contained a decisive clue as to the respective individual's biographical self-construction. In the case of Giulio, it is evident from the start that diagnosis indeed does, at time of interview, assume the position as the crucial event in relation to which life breaks down in a *before* and an *after*. While by far most respondents reported to have experienced diagnosis as an intense shock, only a few of them were, at time

indicate that I have jumped from one such answer to another in order to compose a concise quotation on a specific topic in an effort not to overly try my readers' patience.

⁶ More precisely, given that all the interviews were conducted in Italian, the interview quotes throughout this article are all translations from the Italian. Well aware of the problems spelled by the translation of empirical material which is the object of intense interpretation, I have tried to strike a balance between sticking to the original wording as closely as possible, on one hand, and conveying the meaning of that wording by a less-than-literal translation, on the other.

of interview, still caught up in the aftermath of that shock. This is the case with Giulio, though: as he recounts, while he had managed daily life with ease and guts prior to diagnosis, he lost this ability in that very moment without retrieving it ever since. This is all the more remarkable because, when talking to me, about eight years have passed since he learned about his HIV-positivity.

I shall like to stress that Giulio's lasting crisis was and is not provoked by, or related to, the onset of physical symptoms. He has never suffered from any of the somatic afflictions which may hit people with HIV/AIDS; his immunological situation is actually one of the best among all my respondents. Back at time of diagnosis, his decision to get tested was born out of the suspicion that he may have caught the virus when engaging into an extra-relational adventure. So convinced was Giulio that he had become infected that he repeated the test after it had first turned out negative. By the time when his doubts were confirmed, he had already passed the virus over to his long-time lover. Remarkably, when struck by that news, his partner said that he was ready to share this experience with Giulio - rather than placing blame on him or rejecting him. It is hard to imagine a more supportive reaction to so devastating a news. To no avail: Giulio himself felt so deeply distressed about, as he says, having destroyed his lover's life that he himself broke off the relationship shortly later. At time of interview, he blames himself intensely for having done so - much more than for his original responsibility for having infected his partner. He also intensely blames himself for having quit a promising professional career because of incompatibilities that he had perceived with his needs for medical surveillance; he also blames himself for having lost some of his independence, moving back home to his parents' place for some time, and for earning his living with low-skill jobs now.

In short: Giulio has entered a vicious circle. Throughout the years which have passed since diagnosis, he has increasingly lost ground in his battle with HIV, rather than scoring points. Once he had come to think that his reaction to the

original event of diagnosis ran counter to the way in which he had led his life up to that moment, the past unsatisfactory management of one difficulty came to spur further failures with regard to others. The culmination of Giulio's troubles lies with the attitude which he has come to assume with respect to potential long-term intimate relationships. While having talked about his HIV-positivity to old friends, to his family, to HIV-positive peers, and even to an ex-employer, he has never dared, throughout all of the years since diagnosis and despite of the encouraging reactions obtained to those communications, to disclose his serostatus to a person with whom he would have thought possible to start a lasting loving relationship. Interestingly, Giulio does not perceive any problem with having (protected) sex with partners of whom he does *not* think as potential stable lovers - as he puts it, otherwise he could as well move to a monastery. The reason for throughout the past years, having always left those of his sexual partners to whom he felt seriously attracted, stemmed from his inability to disclose his serostatus. Rather than telling his would-be companions that he had HIV, and thus risking the end of the relationship as a result of the other's possible rejection, he himself made sure it would end - by not telling, and fleeing instead. What keeps this vicious circle going? Why does Giulio not resort to his *old* self's quality of facing difficulties bravely, now that he needs that quality more than ever?

This is the problem. Just as with the other cases selected for detailed presentation, I can not go into detail more than that in the course of the present exposition; I have to limit myself to an illustration of what I have come to see, on close sequential analysis of the case, as the heart of the matter. When confronted with the news that he was HIV-positive, Giulio's previously taken-for-granted nonchalance was shattered. In responding to that news, he was not able to act according to what he had thought of as a quality of himself: rather than facing potential difficulties calmly together with his lover, he panicked. This, in turn, provided evidence suitable to maintain his doubts as to who he is. At time of interview, he wonders whether he really is a coward, or whether he just behaves like one as a

consequence of having HIV. This is to say, Giulio is not always sure whether the lack of guts which has 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 the virus 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"*. In other words: the juxtaposition of two subperiods of his life may be an ex-post construct which inappropriately locates in HIV the responsibility for the change of his character. At bottom, he may really be, and have been in the past, far less brave and outgoing than he now pleases to think. After making this remark, Giulio volunteers:

"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 real 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., seropositivity]. 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, to resume really. I mean, it's like turning back by eight years, you see? Because I feel it, I feel it, within is repressed my true personality."

The contrast between the two subperiods of his life which he sees as distinguished by diagnosis is related, by Giulio himself, to a contrast of character. *Before*, he used to be easy-going and sociable - as he said in the initial part of the interview, he did not let himself get tangled up heavily in daily problems, but handled them in a matter-of-fact way. *After*, the record coherently points to the plain contrary. The contrast between *before* and *after* is framed not just in terms of the existence or gravity of problems to face, but in terms of the way in which it is characteristic for him, Giulio, to face problems. The way in which he used to strive towards a future thought of as open and promising is assumed as a self-description. The blow of diagnosis has rendered that self-definition invalid - and

that invalidation has been confirmed over again throughout the past eight years because it was not a reliable point of reference for the structuration of conduct any longer. Yet its opposite, the weak, timid, and unenergetic self the image of which emerges from the way Giulio did behave over all these years, is not acceptable to him as his true self. Giulio oscillates between old and new: incapable of bringing about a decision (i.e., to either connect back to his old self or to stop blaming himself for failing the standards set by it), he protracts his crisis.

While it is impossible to identify a set of conditions which would necessarily bring about a pattern of experience similar to the one just illustrated, I shall point out a few features which, on comparison between Giulio's case and the reports of other respondents who constructed their self in terms of "invalidation", strike as remarkable. Firstly, there is no necessary relation between the feedback obtained to early acts of disclosure, on one hand, and the ease with which the crisis of diagnosis and the concurrent crisis of the "diagnosis of the self" are overcome, on the other. This is not to say that social support does not matter. Yet, it seems important to caution against the assumption that individuals interpret events necessarily by adopting the social constructs which are most promptly suggested by relevant others. If this were the whole story, Giulio would have retrieved his old "devil-may-care" self on learning of his then-partner's reaction back in the period following closely to his own diagnosis. The "diagnosis of self" may escalate into a biographical turning point even if relevant others do all they can in order not to undermine the individual's taken-for-granted assumptions about self (compare Charmaz 1991: 209). Indeed, as Charmaz (1991: 227) writes with reference to the work of G.H.Mead, the "effects of a past event can reach far beyond what other participants have ever intended. The shaping of the self continues in the mind of the man or woman who relives, and re-evaluates, the earlier event" in the course of an ongoing inner debate. Secondly, on a similar line, a sense of belong-

ing to one of the groups which were hit hardest by the HIV-pandemic does not necessarily prevent the individual from experiencing positivity as a personal crisis - a crisis of identity which may keep them for many years from disclosing their serostatus specifically to the other who is, by means of some mental connection, associated to the onset of that crisis. Thirdly, then, disclosure of serostatus, and fear thereof, may be tied up intimately with the crisis of identity which was first triggered off by the diagnosis of HIV - a crisis which may be unrelated to the fear of stigma on moral grounds which is usually deemed responsible for the HIV-positives' unease within their social environment.

Reinforcement

"Sure" (and ask you for a mo) "Yes, also because there's a metamorphosis, with HIV" (That's what happened to you?) "A double one, in the sense that there's been the first metamorphosis in the moment in which I have come to know it, and the second one in the moment in which I have reacted, in the sense that anyway, when you are told to be seropositive, you enter into a sphere completely different from the one which belonged to me, which is why I started to live in neglect of HIV-AIDS, and so forth and so forth. Hence, silence, loneliness, depression, and so on and so on. Last September, after also concluding an intimate relationship, I said 'that's enough, now I am going to live again!', that's to say, seropositivity yes or no, I don't care. I should begin by mentioning that I do not have a past as a drug-addict, I do not have a past as a prostitute, and so on and so on. [I come from a] Most normal family, basically [my main activity was that] I studied, after finishing school I have met this, a guy in the gym, which anyway means a healthy environment. (...)"

Veronica did not even let me finish my initial question: off she went with a flood of words (which continues for several more pages of transcript). There is no other one among the many cases of biographical reinforcement in my group of

respondents which would match her juxtaposition of periods in clarity. The second of those periods, spanning from diagnosis to the moment when she reacted, closely resembles what I have analyzed above as "invalidation" - except that it is a stage now overcome. In the case of Veronica, post-diagnosis life breaks in turn down in two distinct phases. The second of these, which extends to the time of interview, constitutes a return to her pre-diagnosis past in important ways: Veronica has started to *live* again. Just as with Giulio, the period following directly to diagnosis was experienced as plainly opposed to life.

In her case, though, moral considerations played a constitutive part for the disruptive effect of diagnosis: the sphere into which she was thrown by diagnosis did not belong to her, because she stemmed from a normal and healthy social background (note the transition from the unpersonal use of the second person to the first person singular in the above quote). In short: she thought of herself as different from the people whom she associated with HIV/AIDS. Who could have thought that the acquaintance she had made in the gym, and with whom she had started a loving relationship, had been injecting drugs in the past, thus getting infected with HIV and in turn infecting her? It is this relationship which she mentions as having come to an end "in September", i.e. roughly six months before the interview. Throughout the months preceding that separation, she had cared for her boy-friend: he had come to develop manifest AIDS. Veronica was thus kept from an active social life partly out of consideration for his needs; partly, her restrained level of social activities was due to her shame of having contracted a condition which she herself, prior to her own infection, had associated with the scum of society. The crisis of identity triggered off by diagnosis has a major component related to the difference between the moral image of the groups most affected by HIV, on one hand, and Veronica's clean and sober middle-class background, on the other. This contrast is not an abstract one: it extends to Veronica's way of thinking her self. The clash between the image of deviance and decay, on one hand, and the ideas Veronica had held about her life and self before diagno-

sis, on the other, gives rise to a double "metamorphosis" - to a loss first, and the retrieval later, of her sense of identity. Prior to diagnosis, her conception and style of life were rather upstart: despite having just left school, she worked hard to enjoy an above-average standard of life. Correspondingly, she held a specific view of herself - a view which she has now resumed:

"I am not a person who is easily satisfied; I always want to arrive at the top; I am ambitious. And, you know, initially seropositivity meant to me like: 'babe, up to now you've been dreaming, forget all those healthy - your ambitions, your aspirations and get your feet down to the floor. That is, you're like that now; tomorrow you'll be diseased and moribund in the hospital'. That's how I first thought about it; that's why I fought against it."

Veronica's double metamorphosis can hence be understood as a shift away from and back towards her old description of self as upstart and ambitious; the devastating effect of diagnosis was due to her understanding of HIV as sharply contradicting that self-image both in terms of morality and life-expectancy. Throughout the roughly three years of neglect and depression, Veronica did not have a valid self-description any more by means of which she may have structured her conduct: the association of deviance and decay to her medical condition had suspended the validity of her old self, while failing to supply an acceptable substitute. To be "alive", for Veronica, means to live similar to the way in which she used to live prior to diagnosis; to have now, even despite HIV, retrieved the connection to the way in which she used to live means to have strengthened the belief that she, as a person, is distinguished by the literally vital aspects of her self which had characterized her before diagnosis - all the more so since, as she recounts, many people with HIV just use that condition as a pretext for abandoning themselves to self-pity and passivity.

In contrast, Veronica's reaction was triggered by *"the wish to still believe in my projects, the desire to still do so many things. This, really this strong need from*

inside, which I had repressed for three years, my self." Rather than just reporting to have resumed old projects, she reports to have resumed her old self - a self which was *distinguished* (by its quality of nurturing and pursuing high-flying ambitions) both from her old mates and, all the more so, by the bunch of fellow-PHIVs who do not even try to control their lives. This does not mean that Veronica thinks of herself as exactly the same as before: "*there have been a lot of changes*", she says, due partly to the difficult experience of HIV, and partly to the fact that she is in the process of growing older anyway. Still, "*there were a lot of connections relative to the first 20 years*" of her life. There is a sort of continuity between the period prior to diagnosis, on one hand, and the period after the second metamorphosis, on the other; the period in between the two does not make part of her self, except for having taught her a lot about her true goals and desires.

Among all my respondents, Veronica was the one who most clearly articulated moral concerns as a major component of the crisis triggered by diagnosis. Veronica's case shows how well moral stigma, on one hand, and the shock of having one's life-expectancy cut sharply, on the other, may go hand in hand in disrupting a vital self-definition which had previously been taken-for-granted. Veronica's ambitious self was invalidated both by the image of impending death *and* by the image of moral sloppiness which she attached to her medical condition- until she resolved to retrieve her old self *despite* of those images. This very resolution, which found its practical expression in the decision to break her silence and start disclosing her condition to friends and acquaintances, constitutes the basis for her biography to be constructed as a reinforcement: the pursuit of her ambitions face-to-face the perils posed by HIV is all the more distinctive.

When comparing Veronica's case to the other respondents who reported to have largely resumed their old lives and selves after an initial period of disorien-

tation and loss, she stands out as quite particular: in most other cases, passage from crisis to a new sense of normalcy came about with the help of a shared sense of belonging to one of the groups most affected with HIV, namely the gay community. A first observation to stress from a comparative point of view thus regards the relevance of group membership for the integration of the event of diagnosis into one's biography (compare Carricaburu/Pierret 1995). Most of the respondents who constructed their selves in terms of biographical reinforcement had established contact with a support association for the HIV-positive quickly after diagnosis - sometimes in a matter of days. Not coincidentally, all of those who reacted so quickly were gay men: access to support groups for people with HIV is greatly facilitated by a shared sense of belonging other than HIV. Given that, especially throughout the pandemic's first decade, most such groups were promoted by the gay community, this clearly helped members of this particular population as against other people struck by the virus.

Secondly, the beneficial effects of a shared sense of belonging are likely to continue in that the conceptual tools offered within such groups can more readily be adopted if there is a fit between key elements of one's previous sense of identity, on one hand, and the identity of the group with regard to which those conceptual tools have been elaborated, on the other. The possibility of interpreting one's personal history within the framework of a broader collective history can be highly reassuring. Thirdly, though, there is a potential hitch to such adoptions of collective interpretations for the resolution of one's crisis of identity: those interpretations may simply not quite fit the problem which they are used to resolve. On close interpretation, several of my interviews turned out to reveal considerable inconsistencies between proclamations such as the continuity of life despite HIV or the manageability of the condition in result of a proper frame of mind, on one hand, and the respective interviewees' ability to argue and elaborate on those points with reference to their own experience, on the other. In extreme cases, those inconsistencies amounted plainly to a gap between the crisis of identity into

which the individual had been plunged by diagnosis, on one hand, and the conceptual tool kit used to fix that problem, on the other. The self-description which an individual adopts in harmony with the collective interpretations taught within a self-help group or support association may simply not relate to the doubt about his or her identity which was initially raised by the news of diagnosis.

Fourth and finally, then, Veronica's case is indeed exemplary in what regards the irreducible character of the individual's decisions and actions relative to the input of relevant others. Veronica resolved to dare disclosure towards her friends even though she had experienced heavy blame for having caught HIV on the part of her parents. Once more, this is not to say that social reactions do not matter: one respondent who had faced the most outrageous stigmatization by her husband had come to see herself as literally contagious, and gratefully noticed my lack of concern when accepting her offer of a tea, to be taken from the sort of cups she also uses. Yet, the interpretation of HIV which is currently most renowned among social scientists misses out on the crucial consequences specifically of the event of diagnosis. True enough: "There is a collective dimension to HIV-infection that shapes the individual's experience" (Carricaburu/Pierret 1995: 71). But how does such shaping come about? I believe that individual experience is irreducible to the social categories by means of which it takes shape. While the association of HIV to moral deviancy and imminent death definitely is a social construct, the repercussions of those associations at the level of self can not be predicted in a general way. What HIV's infectivity and potentially lethal effects *mean* to the individual on the basis of his or her personal history can not be properly understood by recounting the history of the groups most affected by this disease.

Continuity

"You know, I have perceived a very gradual transition. That means for me HIV, the diagnosis of HIV, has not been a turning point in my life. If I think about before, the main difference, but it's a very fuzzy 'before' really, a 'before' which is not necessarily prior to that date, the main difference, in my view, is the, the major or minor consciousness of a problem. 'Before', relative to HIV, 'before' to me has this meaning - it does not mean major happiness or thoughtlessness, if you know what I want to say. Because, as I told you, for me it's all been very, very gradual. I have needed a lot of time to understand what it was. That's to say, the moment in which they told me as such has not been a significant or important moment."

The two patterns of biographical self-construction which I have discussed thus far, "invalidation" and "reinforcement", add up to something like the standard process of self-constitution as mortal. It is important to caution immediately against the possible wrong implication that there be anything like a necessity of transition from one to the other here: some people may get stuck in invalidation without ever overcoming that pattern. That said, though, the adoption of a dynamic interpretative perspective to the one-shot interviews which I conducted enables us to perceive the pattern of invalidation as a *stage* within the process of self-constitution as mortal: to all those who have recounted their biography in terms of reinforcement, diagnosis had set off an initial crisis of variable length which, as is clearly discernible from the remarks made on that period by the respective interviewees, would have been recounted in terms of "invalidation" at that time. For representatives of both patterns, the moment of diagnosis constitutes a crucial life event around which thoughts and actions have come to be centered for months or even years.

In contrast, there are biographical self-constructions in which the moment of diagnosis does not stand out as the crucial, or even a crucial, life event. While

this was true for a few of my interviewees only, these can in turn be subdivided in two groups: respondents who report not to have experienced diagnosis as a particularly meaningful moment at all, and respondents who do not attribute the status of a biographical turning-point to diagnosis albeit recounting to have experienced it as a shock at that time. While interesting questions are raised by the second of these subtypes as well, I will concentrate on the first one in accord with my policy of discussing the most extreme case within each pattern. Sergio's case is indeed extreme: as he relates subsequently to the above quote, he does not even recollect well the situation in which he was told about his positivity. This is all the more surprising since Sergio's diagnosis occurred as early as technically possible (i.e., right after the virus had been identified and means for its detection from blood samples developed): "*I think it was in [the year 19]83*". As is well known, this was a time when this odd new condition was associated to almost imminent death: as Sergio recalls, shortly before being diagnosed, he had read a newspaper article on deaths among the gay community in San Francisco. How come that Sergio, who was just 23 years old then, did not experience a shock when being confronted with a news which seemed to imply his own imminent death?

Having had life-long experience with managing another chronic and highly unforeseeable condition, namely haemophilia, Sergio was used to face trouble when it arised - rather than when first learning such trouble *may* arise. Differently from the various episodes of hepatitis which he had experienced in the past, "*to have come in contact with that thing [the virus which would later be called HIV] had not caused me any harm for the moment, you see, it was something which did not cause me anything, right?*" Given that his experience of haemophilia had taught him to base judgements on his state of health primarily on his own observations, rather than on statements by his doctors (indeed, Sergio has learned to acutely observe medical staff with a view to its level of expertise, concluding that it often be highly insufficient), he simply did not take for granted that this virus would

provoke his death any time soon. Until further notice, Sergio would not feel threatened.

Such notice arrived years later, when his T4-cell count fell quickly for an extended period of time, dropping below a level which he had defined as critical. Sergio figured that, if this process continued at the same speed, he would be left virtually without an immune system before long. "*This is when I started to feel dreaded in a systematic way*" - for the first time in his life, Sergio recounts, he was most intensely concerned with his health and survival in the absence of what he would classify as a concrete somatic problem. *This* was a shock to him: he had not thought of himself as being susceptible to such feelings. Together with his health, what became threatened was his self-description as sufficiently rational a being not to ever succumb to dread.

Now, as a result of a detailed case-interpretation which can not be fully presented here, I believe that it is because of Sergio's ability to rather quickly resort to an updated form of that old self-description that he did not construct his biography around the marker event of this episode of dread. Indeed, Sergio reports that he managed to maintain a distinctive style in handling that dread - distinctive in particular as compared to the dread of his ex-girlfriend (who had caught the virus from him). As is evident not only from Sergio's narration, but also from the interview which I conducted with his ex-girlfriend, she had intensely feared, and expected, the worst possible outcome from the very moment of first suspecting that she may be infected; she had hence worked herself into a state of constant terror about her prospective physical decay and loss of control. Sergio had tried to contrast that attitude from the start - with rather negative consequences for the relationship (she felt ill understood in her concerns). Yet that attitude and the concurrent self-definition helped Sergio to quickly gain composure when himself coming to intensely dread an event which had not yet manifested itself: "*I knew that my, right?, my dread could not be like that [like his girlfriend's one]*". While

his girlfriend tended to abandon herself to her dread, he kept on making observations as to the circumstances and effects of that dread, and continued to contrast it with the thought that, after all, it may be exaggerated or plainly pointless. At time of interview, Sergio thinks he is "*immune against that sort of dread*": "*I am not a hypochondriac*". Rather than having come to feel more vulnerable by negative feelings than he was prior to his attack of dread, he sees himself as further strengthened.

Beyond the specific features of this personal case, Sergio's story is instructive in two important respects. Firstly, background experiences shape the perception of diagnosis decisively. This is not to imply, of course, that every person with haemophilia who comes to be diagnosed with HIV reacts the way Sergio did. Yet, the very qualification of diagnosis as an *event* constitutes an assessment made by the individual on the basis of a series of assumptions. The experience of diagnosis as a disruptive event is predicted mainly by the following two factors: (a) to have previously taken an extended future dimension of conduct and self for granted, and (b) not to have, in the past, developed skills as to the management of high degrees of uncertainty with regard to one's future. Haemophilia is a background experience which may make a difference in both respects. Secondly, self-construction in terms of continuity seems to bear a high degree of affinity with an in turn continuous pattern of communication of and about HIV. While a cleavage between early and late acts of disclosure could be observed in a great many respondents from other patterns, Sergio made efforts at turning his condition into a topic of conversation with remarkable vigour - despite of the rather discouraging reactions he obtained: by and large, the responses to his disclosures were manifestations of either (alleged) indifference or panic. Again, it seems fair to remark that specific patterns of biographical self-construction as seropositive can not be accounted for adequately in terms of social reactions to disclosure as a person

with HIV; rather, the individuals readiness to expose her- or himself to the risk of obtaining discouraging or even clearly negative reactions seems to be related to the state of biographical self-construction.

Void

"That means, my life before, that means it was really regardless, you see? That means I now succeed in understanding that, I never accepted any responsibility, you see? That means I always did what I enjoyed, really in the sense of what gave me pleasure, and - first, there was me, and then there were the others, you see? That means, I don't quite understand what you mean by 'my life'."

This is not the very first answer given by Paola in the course of the interview: it is her response to my effort at relaunching the initial question. My first attempt at learning about her life before diagnosis got stuck: Paola responded to it by recounting a series of instances in which she said she felt restrained now as compared to previously. Given that I had, prior to the interview, had occasion to observe Paola's ability for staging a show (during the session of the support group for seropositives at which I described my research and asked for co-operation, she was at the center of attention: after hours of seek-and-hide, she finally admitted to having recently relapsed into an episode of intravenous drug-use), I had a heightened sense of the possibility that she may be trying to foster an impression on me. From the very beginning of the interview, I thus felt I had to be particularly careful not to be fobbed off with a version of events which Paola had chosen to present to me, rather than with a honest account of her thoughts. And indeed: the series of instances with which she illustrated her general remark that her life had become much more restrained after diagnosis sounded shallow to me. The risk of causing harm to her health by walking the street with wet hair did not seem to bother her excessively (she did not discontinue that practice); the need to

restrict herself to jobs which would not require sustained physical effort did not appear plausible as a deeply felt concern (in the course of the hide-and-seek at the support group, it had become evident that she did not enjoy working at all, not to mention hard physical work); when naming disclosure of serostatus as a third area of concern, she limited herself to generalities which appeared not to connect to her personal experience.⁷

⁷ In order for the reader to be able to judge whether this "hermeneutics of suspicion" seems mislead, I wish to document the sequence preceding the above quote:

"... How was my life before?" (Yes) "coming to know about my seropositivity?" (Exactly) "It was more unrestrained." (In which way?) "It was - that means, it was not tied down, that means it's more restrained now. That means, you are, I am much more limited now than before." (Can you extend on that? In which sense were you more unrestrained? In which sense are you limited?) "That means, more unrestrained because I did not have this concern as to what you can do, right? Be it in physical terms, be it mentally, you see? That means ... that means also with regard to the most banal things, you see? That means I did not ... I mean perhaps I now say something stupid, right?, but what before may have been a lack of attention may cause real harm now, you see?" (You mean with regard to sexuality, for example?) "No, I am referring also - to lack of care, you see? When it rains, I do not use an umbrella (laughs). before that was a lack of care, because I got wet. Now it may spell real trouble because I may catch something, you see?" (That means, you have to pay more attention to certain things.) "Then also, something more serious, with regard to work. You are limited because you have to do - that means I have to do work which would not be too demanding physically." (But is that a serious limitation for you?) "Yes, I feel that's a serious limitation. Also, I don't know, the examples I make are most ... when you know somebody (...), the problem: do I stage a show? Do I tell, or don't I? Will I be accepted, or won't I? You see? It also depends on, well, how you are. I for example am ... very sensitive, you see? That means ... I do not like to, to hide myself, you see? But at the same time, - that means, it's not important whether or not you say it, but - because you either say or you don't, that's

The information which I had obtained when contacting the support-group to which Paola belonged had thus assumed relevance for the interview situation. Yet that prior contact did not bring about one-way information only: when being interviewed, Paola knew that I already knew about her past as a drug-user. While some feet-dragging before "confessing" that past to me makes for an obvious reason for her to respond in a somewhat evasive way to my initial question regarding her past life, it is hence fair to suppose that there be another dimension to her way of acting. Right after having said that she does not know what I mean when asking for "her life", Paola will recount that her past life was the classic history of a drug-addict. This may potentially reinforce the impression that she just needed to buy some time before voicing a statement which to make cost her a lot. But there is a second interpretation - an interpretation which takes Paola's words literally. Having spent most of her youth with activities related to the purchase and use of drugs, Paola may indeed not have been too sure as to what characterized *her* life - and what characterized *her* as a person. Indeed, on the basis of the accounts of Paola and several other former drug-users among my respondents, I believe that the "*classic history of a drug-addict*" results, at the level of self-description, in an almost complete deprivation of self: in the absence of distinctive self-definitions which may help structure conduct. I will briefly illustrate this interpretation with a view to Paola, to then have a look at other respondents.

In the case of Paola just as in several others, the diagnosis of seropositivity did not trigger a change of habits: "*I lived as if nothing had happened*". After diagnosis just as previously, daily life was centered around buying, selling and taking

relative, right? What matters is that in your mind you feel this obligation to tell, not to tell, you see?" (*Is that a constant aspect of your life now?*) "Yes." (*Let's take a step back, and then we'll talk about that a bit more. Tell me a bit about what your life before looked like. What counted most in your life then? What did you do?*)

drugs. Paola was diagnosed about six years before the interview at the age of 23; according to her own indications, she had been injecting drugs since she was 16 years old, and had continued to do so on a regular basis until 18 months before the interview. Similar to most of the respondents who had become infected by intravenous drug-use, the knowledge of being seropositive did not induce her to stop injecting. When taking one of those periodical breaks from drug-use which she compares to the temporary breaks from daily life taken by ordinary people with the declared purpose of resuming it (*"to stop [injecting] is for a drug-addict a bit like taking a vacation for a worker"*), she perceived the need for a lasting change (*"if I had resumed [injecting] again, I would not have stopped any more"*). But differently from ordinary people who may, on thinking about their daily lives during the holidays, consider the case for change, when looking back at her past as a drug-user, Paola did not find any anchorage point which would have helped her to reorganize her life: *"when you take away the heroin from your life a huge hole is left in your soul - a hole so huge that you don't know how to fill it."* Initially, her emerging awareness of being HIV-positive only added to that desperation. Not only did she feel to have simply wasted most of her past life: her medical condition made a normal existence look impossible in the future as well. Only when joining a support-group a few months before the interview, Paola started to deal more intensely with her condition. In particular, she started thinking more intensely about herself: the group made her notice aspects of her character of which she had not been fully aware previously. This interaction with the support group turned out to be highly ambivalent, because the aspects of self which were thus made evident, especially Paola's ruthless egoism, were valued negatively by the other group members. While helping her to know herself, the group insisted that she should change.

Now, Paola's reaction to this ambivalence highlights the dramatic character of the void of self which she had experienced - and which to fill was her main concern. She gratefully accepted her peers' hints at her quality of being an egoist,

while rejecting the expectation that she would have to change which resulted from the negative valuation of that quality. *"I feel it's not necessary for one to change: what really matters is that you know how you are"* - it is actually by defying her peers' expectation at improving her self that Paola manages to strengthen the status of egoism as a distinctive aspect of her character. If we re-read the opening quote of this section in the light of this interpretation, it becomes evident that her "me first"-attitude is indeed the only way in which she can qualify *her* way of life - and that this understanding of herself has emerged with some degree of clarity only *now*. In her desperate need of establishing some sort self-identification at all, Paola sticks to the first candidate on offer - consistent with that attribute of self, without much caring about the reactions of others.

On the first sight, the above interpretation may seem far-fetched. Yet Paola's remarks on the void left by her habit of injecting drugs are echoed by several of the other five respondents who were infected by shared needles. Given that intravenous drug-use had dominated all of the respective individuals' youth and early adulthood, the emerging awareness of being threatened by premature death cast its shadow back on the past in a very specific way. Daily life, Vladimiro recounts *"was centered around the drug"*, which is why that period is now thought of as *"a life thrown away"*. The one thing Orsola has retained as a valid feature of her life with the drug is that she has come to know what she *"want[s] to flee"*. When learning about her serostatus at the age of 26, Alessandra was dreaded not only by the thought *"of dying, of leaving everything, of not having time any more to do anything"*, but also by the thought *"of never having done anything, [which is] even worse"*: *"at that time[while injecting heroin], I was only that, at that time the one existing thing was that (...), I was only that, I did not know myself otherwise than in that"* (Alessandra). The awareness of being HIV-positive further reinforces the existential desperation which may result from prolonged drug-abuse especially throughout adolescence. As a result, intravenous drug-users are particularly likely to blame themselves for what has happened to them: differently

from many gay men, the pattern of behaviour which has led to the transmission of HIV is usually not sheltered against bitter self-reproaches by relating to a relevant aspect of one's present sense of identity.

Not all of the ex-users among my respondents constructed their biographies in terms of void, though: this is actually the case only with two of them, namely Alessandra and Paola. In one other case (Orsola), intense indoctrination with the rhetoric of self-actualization had resulted in a narrative in terms of exemplary adaptation; only below the surface of that official success-story could I discern the desperation of a woman who still felt to be at loss of herself while knowing she would soon die. In two other cases (among which we find Vladimiro), the narrative was established in terms of continuity: little or nothing was reported to have changed by the respective respondents, who had both established everyday routines not reducible to drug-use (family life in the one and a rewarding professional activity in the other case) before discontinuing that habit and thus becoming aware of their serostatus as entailing a problem. Finally, one respondent recounted her life in terms of reinforcement: after first having been intensely shocked especially by the risk that her new-born child may have caught the virus, too, this woman then resumed control of her life precisely with a view to her quality as a mother - a mother who, given that she bore responsibility for having to leave her child a semi-orphan some time in the future, was ready to sacrifice herself entirely, until the end, for the well-being of her child. In short, even though a retrospective assessment of the period of drug-abuse as having left a huge void is a rather general feature of ex-users, a self-construction according to the pattern void will be established only if no events or activities have emerged (either before diagnosis or from the time of diagnosis to the moment in which drug-use has been discontinued, and the knowledge of being HIV-positive thus reached awareness) which would fill that blank. One last remark: differently from other patterns discussed above, the social environment seems to play a vital role both for ex-users to realize that HIV may constitute a serious problem, and for

the identification of aspects of self which may help them to organize a life without the drug.

Switch

"(...) I really started to panic. A panic which lasted for a few days. Then, in response to the pushes from my brother who scolded me, who tried to, to shake me up, at some point there really was the release. The release in the sense that, I really had the feeling, when this thing started to change aspect, that is to say - I started to change. I had the feeling as if I, until, during that period there, had been leaving like in a bubble. That's to say, apart from everything and everybody - that's to say, I observed [what was going on], but did not do anything to improve my situation. (\\) At some point, this thing came apart, that's to say, I really had the feeling that this, this wrapping had broken apart, and I slowly turned, let's say, I again started to become normal again, in the sense that, I managed to talk more, right?, I managed to pour my heart out, I managed, I succeeded in listening to what they told me. (\\) This is a bit let's say the experience of before and after, because now, for example, even if usually, you know, the character does not change in just one moment, but yes, it's much easier for me to talk to other people."

The episode recounted by Francesco here did not follow immediately to his diagnosis, but happened roughly ten months later in the course of a medical problem which made him dread he may be about to die. Francesco had been diagnosed roughly a year before the interview at the age of 46; as further bloodwork soon revealed, his T4-count was already down to almost zero. The first months after diagnosis were characterized by a continuous health emergency (including a hospitalization for pneumonia); yet differently from the episode recounted above, Francesco never thought he may be close to death. That thought occurred to him only when getting trapped on a remote island without proper medication for treat-

ing the fungal infection which kept him from eating sufficiently. Given that he had already lost dramatically much weight throughout the preceding crises, Francesco got seriously scared. The above set of quotes stems from a section a few minutes after the start of the interview in which Francesco's account of the difference between "before" and "after" culminates in the conclusion that he is much more ready now to open up towards his social environment than he used to be. Similarly, a bit further on, he states:

"There really was a turning point, yes ... Really a remarkable change, as I told you, as compared to how I was before, in short. And I am doing much better, because I am much calmer, more relaxed, you see, don't - that's to say, almost everything changed that's to say all the - everything changed, in short, it changed for the better, I have to say."

Strikingly, this contrast applies not only to the distinction between the period of acute crisis, on one hand, and the situation at time of interview, on the other: it refers to the interview's initial prompt, namely the invitation to talk about the period *before diagnosis* as opposed to the present. Francesco's incapability of communicating effectively at the height of his episode of dread was just the culmination of an incapability which had characterized him for decades:

"(...) before, if I was not - grilled, let's say, if there was not somebody who asked me questions, who made me, who" (You did not start on your own initiative?) "I did not start [talking]. Now, in contrast, I manage more easily, more - that's to say, to express what I carry within mys---, I manage more easily, before not, absolutely. There really was a need of a person who would pose me precise questions. (\\) You see? There's always been this ... this handicap [English in the original] (...) even when I was a boy, when I was 17, 18, 20 years old (...)."

Francesco is the only one among my respondents to construct his biography in terms of a swift switch from an old self-definition to a new one - and his case is

very special indeed in many other respects as well, thus setting him somewhat apart from the rest of my interviewees. For a start, shortly after learning about his positive serostatus, he was confronted with the even worse news that he had already reached an advanced stage of AIDS. Secondly, this news reached him at a rather mature age (the second highest among all my respondents): when understanding that his lifetime may be about to expire, Francesco had lived for about two decades more than most respondents at time of diagnosis had done. Differently from the many young adults in my group of interviewees, his character can thus be assumed to have already been stably formed. The sudden change of self reported by Francesco is thus all the more surprising; it can hardly be explained without taking into consideration, thirdly, that the aspect of self with regard to which that change came about had previously been valued negatively by Francesco (it had long constituted a "handicap", as it were), and fourth, that his brother intervened in a highly remarkable way. When talking aside the panic-stricken patient's bed, the brother posed the alternative most clearly: either Francesco would react - or he should indeed get ready for the "*passage*", as he put it.

Once the situation was framed this way, it was impossible to go on living the way Francesco had used to live. We as second-order observers may be struck by the fact that he attaches the label of a handicap to his old self, rather than to his condition of severe immunosuppression; we may engage into remarks as to the deceptive nature of the alleged secondary gains by means of which individuals manage to accept a decrease of quality of life by finding some positive aspect in it. The point which I would like to make with regard to Francesco's account is more simple: biographical constructions in terms of a sudden switch of self are one among the options potentially available to persons with HIV or AIDS. I am struck by the speed, scope and determination of the change perceived by

Francesco with regard to his self. As we will see right now, Francesco's way of assessing the impact of the thought of death on his self differs from that of all other respondents.

Awareness of finitude and its effects

Above, I have distinguished five patterns of biographical self-construction with a view to the status of the diagnosis of HIV or AIDS. Across that variety of patterns, the knowledge of being HIV-positive has turned out to be tied to specific aspects of self. In each of the exemplary cases which I discussed in some detail, the awareness of one's own mortality has become connected to a particular feature of self. Thus, Francesco recounts that the intense dread of death which he experienced at the height of a medical crisis brought about a sudden switch of self with regard to communicative openness. Paola was at a loss of any distinctive feature of self capable of filling the void left by a decade of drug-abuse - until peers suggested an aspect, namely egoism, which she gratefully accepted as her self-definition. The continuity of Sergio's self relies specifically on his self-observation as being able of handling any sort of fears, including the fears potentially evoked by HIV disease, in a rational, matter-of-fact manner.

The three patterns mentioned thus far are all somewhat special - in all of these three variations, my general interpretative model of "diagnosis of self" has served as a means of contrast against which the specificity of each particular pattern has emerged more clearly. The patterns of "invalidation" and "reinforcement", in contrast, can be seen as the consecutive stages of what may be called the standard process of self-constitution as mortal - except that some individuals get stuck in the first of those stages for extended periods of time in an apparently irremediable way. Because diagnosis of HIV had caused Giulio to lose faith in his previously uncontested conviction to be able of handling any difficulty of life with ease, he indeed got more and more trapped by difficulties: the invalidation of his old self lasted on and on. This need not be: the retrieval of her old self-definition as an extraordinarily ambitious person helped Veronica to break the ban of a vicious circle similar to the one in which Giulio keeps on being caught.

In all of these five exemplary cases, the utterly personal attribute which has assumed particular relevance for the construction of self does not, as such, carry general interest. Who cares whether Sergio constructs the continuity of his self with regard to fearlessness or, say, polygamy? Nor is it surprising to note that those attributes bear a close relation to the knowledge of seropositivity, and specifically to the time when that knowledge was first communicated to the respective individual - after all, consistent with my research strategy, the patterns of self-construction are established with a view to the difference potentially made by the diagnosis of HIV. Observations which can claim general sociological interest start right here, though.⁸ First, beyond the particular articulation in individual cases, it seems noteworthy that the knowledge of HIV-positivity typically affects a specific aspect of self, rather than exerting its impact indiscriminately on all of the assumptions previously held on oneself. Second, the particular features of self which bear crucial relevance for the biographical self-constructions of my exemplary cases were singled out by the respective respondents themselves expressly as self-descriptions. This implies that the process of self-constitution as mortal is intrinsically connected to the establishment of a reliable self-definition. The question to which I would now like to turn hence regards my respondents' explicit assessment of the *effects* of the thought of death on their self.

Before diagnosis, the thought of their own mortality was not relevant for the way in which my respondents thought about themselves. The strong awareness of their own finitude which was triggered by diagnosis thus added a dimension to these individuals' self-reflections which had previously been absent. If the diagnosis of HIV would not have come about in that particular period of life, and if

⁸ I shall consider the relationship between biographical self-construction and disclosure toward others in a separate paper and focus exclusively on the issue of biographical reflexivity here.

the intense thought of death would thus have forced its way into consciousness at a different point in time, its effects on the affected individual's sense of identity would or, to say the least, could have been different. If the test would have turned out HIV-negative, all of one's life may have taken a different turn. In short, the repercussions of diagnosis on the self may retrospectively be observed as contingent by the very persons affected. This means that my respondents' retrospective reflections regarding the effects of diagnosis on one's life and self are in turn observable, by us second-order observers, with respect to the relationship between self-knowledge and self-transformation.

Any observation which a human being may make regarding her or his self is self-cognitive - including the statement "I have changed". That said, though, it is important to distinguish between two fundamentally different ways in which observations on the self can be made. Firstly, the self may be conceived as having been decisively shaped by a specific event or experience - such as in the statement "I have changed" (as a result of X). Alternatively, the self may be conceived as existing independently of any particular experience: whatever circumstances may come to alter one's idea about oneself, those modifications are conceived as revealing aspects of the self which had previously gone unnoticed, but which were nevertheless present already. This second approach is handily evident from statements such as "I discovered myself" (as a result of X). While in the first approach, the cognitive dimension is implied by and subordinate to the transformative dimension, the opposite is the case with the second approach: changes of self are here implied by and subordinate to the enhancement of self-cognition. By the same token, the character of a life-event which is conceived as having helped bring about that enhancement of self-knowledge is not framed as decisive in the sense in which an event conceived as having brought about a change of self can be termed crucial. The very semantics of self-discovery implies that the respective event has made a difference only with respect to the degree and speed of self-knowledge (and, eventually, with regard to the order in which different as-

pects of self have become manifest in self-consciousness). In contrast, the semantics of change proper allows for much wider a range of variation: depending on which event happened, and when, the present sense of self may have come to be entirely or largely different in its absence.

My exemplary cases have each singled out a specific aspect of the self as the self-description with regard to which their biographies are constructed in terms of continuity, invalidation, reinforcement, void, or switch, respectively. Those constructions and aspects all relate to the knowledge of HIV-positivity. The question as to the effects of diagnosis on the self thus bears crucial relevance for the status of the self which is hence established. Quite evidently, my respondents' explicit assessments of the effects of the thought of death are not disconnected from the respective patterns of biographical self-construction. The five patterns of self-construction which have emerged from my empirical material may be ordered along the dimension "scope of change", with the patterns continuity and switch representing the opposite poles. Yet, it would be deceptive to dispose of the question this way. First, degree of change does not coincide with speed of change. The pattern of continuity, for example, may include individuals who have noticed lots of change, albeit in a continuous way. Second, degree of change may not be predictive of its qualification in terms of self-cognition. It is possible to imagine cases who report to have changed completely, but who conceive of that vast amount of change in terms of enhanced self-knowledge. I will thus now briefly turn to my above exemplary cases to provide an empirical basis for the ensuing considerations.

The exemplary representatives of all five patterns of biographical self-reflection indeed talk about change when assessing the effects of the thought of death. This is true even of Paola, who has (as will be recalled) rejected the idea that she may have to change character. For her, the change consists of the need to establish a distinctive self-definition, i.e. to know herself better than she had previ-

ously done. After joining the support-group, she started thinking of her positivity more than previously and, prompted by her peers, undertook "*this work of looking into myself*". Yet the quality of self thus revealed, namely her egoism, did not provide her with much of a clue as to how she may now structure her life: the shadow of her past still looms large in that she has "*lots of projects and none*". Paola says she is scared by the process of dying and all the suffering it may involve, rather than by the idea of death as such. The thought of death does not play an active role for her self-construction - possibly because she was half aware, during her life as a drug-user, that she continuously risked dying by an overdose. In Paola's case, it is difficult for us as secondary observers to discern the effects of the thought of death as triggered by diagnosis, on one hand, from other factors (namely the effects of her suspension of habitual drug-abuse and of her involvement with peers), on the other. Former drug-users among the HIV-positive may be inclined to view the prospect of their own death as something unreal (given that they have often made return-trips to that barren land in the past); by the same token, the image of an ugly death of slow physical decay and prolonged suffering (as opposed the mystified, ecstatic death provided by heroin; compare Des Jarlais/Casriel/Friedman 1988) may be specifically likely to haunt ex-users.

Differently from Paola, an active use of the thought of death for the work of introspection is reported by Sergio, the exemplary case for the pattern of continuity. When now rereading the beginning of the interview with Sergio, we can notice that, while stating that diagnosis did not constitute a turning point in his life, he acknowledges a difference between some cloudy notion of "before", on one hand, and the present, on the other: "*the major or minor consciousness of a problem*". When later extending on this subject-matter, Sergio says that he needed a lot of time to realize that HIV was, despite of its asymptomatic character, in some way present in his mind. He says he noticed that presence precisely because of its effects: "*It's like a seed, right? Very slowly, some little leaves have*

emerged, and I have understood that it was there." Throughout the first years of his life with the virus, he insists, he did not forget or deny that he was positive:

"I just did not know. That's to say, how to say, it's like having an object at home, and you don't know what to do with it. Then, some day, while you are doing some work, you say 'ah!' [he laughs], 'I may use the hammer to beat the nail'. In this sense I have understood it."

The area of "work" for which the thought of mortality has turned out useful consists of Sergio's "inner life"; in this way, as he goes on to explain, he discovers things about himself similar to the way a scientist makes discoveries about his subject of study. Albeit at a completely different level of sophistication, Sergio qualifies his self-reflections in a way which resembles Paola's, namely as a work capable of revealing pre-existing features. The changes of his self which he has noticed in the course of a decade of life with the virus are thus conceived as *"a course which I find satisfactory and which I would define as maturation, you see, as growth"*: the thought of death is understood, by Sergio, to have heightened his self-consciousness without having crucially altered the course of development.

As referred to Sergio's life, this seems a plausible perception: after all, there were no radical breaks. Diagnosis did not constitute a watershed; consequently, the question what would have happened if he had *not* turned out HIV-positive does not impose itself with particular insistence. In contrast, it strikes to learn that the development of her self is conceived as a process of maturation and growth also by Veronica - despite the fact that she spent the first years after diagnosis in deep depression, and despite the fact that she has qualified the two moments which marked the beginning and end of that crisis, respectively, as a double transformation of self (*"metamorphosis"*). While having in the meantime resumed her old self-definition as a highly ambitious person, Veronica does not think of herself exactly the way she used to before learning about her HIV-positivity: *"before, the goal always was to kick over the traces - now the goal is to do*

things well". Yet that contrast is related, by Veronica, essentially to her having grown older: "I don't like to think that I am like that only because I am seropositive. I told you, having caught it at the age of 20, I would certainly have experienced a process of transformation, of growth anyway".

Veronica plainly rejects the idea that the completely unforeseen life-event of diagnosis, which threw her in a turmoil for an extended period of time, and the ensuing lasting awareness of her own mortality, may have altered her self decisively. Her assessment of the effects of diagnosis on her self becomes colourfully evident from the very way in which she acknowledges the relevance of her three years of crisis for the development of the heightened sense of purpose and responsibility which distinguishes her present pursuit of goals from the former one. Rather than as a contingent disgrace, Veronica constructs her HIV-positivity as a necessary experience in order for her to learn more about her true way of being:

"I think it's really a stage through which I had to go, in the sense that throughout these three years I have anyway come to know myself. I have come to know what I like, what I don't like, what does me good and what doesn't. And then, you know, certainly from a, from a sad experience or anyway from a difficult experience emerges exactly the way you are".

A similar view is voiced by Giulio - although he did not yet manage to overcome the crisis of his self-description which was triggered by the diagnosis of HIV a long eight years ago. Although he has been living in a state of continuous distress for many years, and although there are no signs that he may be close to finding a way out of the vicious circle in which he has got trapped, Giulio volunteers:

"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."

He goes on saying that it indeed is very strange to find a positive aspect in his experience, but that he has come to read and analyze himself intensely - without having decided so, i.e. in an involuntary way. Independently of the fact that the reason for this more reflexive attitude towards himself was not joy, but pain, he says, the result is the same: *"to listen to oneself, to know oneself, to understand oneself, to read oneself as best as possible"*. To my question whether things would have evolved that way anyway, he first states that yes, fundamentally yes, because he is a very reflexive person - but that this trait would have been less intense:

"yes, [diagnosis and its consequences] gave it a decisive stamp, you see? A decisive stamp - in fact, its odd because what I miss most maybe is really the fact, the devil-may-care attitude, as I told you earlier, which is the opposite, if you will. Being very superficial."

I agree: it is very odd that Giulio thinks he can establish a continuity between his present self-reflexivity, on one hand, and the regardless attitude which he singled out as the most precious aspect, and most painful loss, of the period prior to diagnosis, on the other. Indeed: did he not state, in one of the passages quoted in my earlier discussion of his case, that he would have to turn back by eight years if a cure should now come to be available to him? Part of what his present reflexivity helps him *"read"* more carefully than ever would thus precisely be the *"true personality"* which he says (in the piece discussed earlier) has come to be repressed within himself. The thought of death seems to allow Giulio to stick to the conviction that his true personality exists independently of the observations he can make with regard to present actions: deep within himself, there lies an image of himself which he has conserved as valid despite its constant defiance by present circumstances. As with Sergio, we can notice that self-knowledge is brought

about involuntarily as a result of lasting exposure to the thought of mortality. Just as the representatives of the patterns void, continuity, and reinforcement, the exemplary case for the construction of self in terms of a lasting invalidation conceives the effects of the thought of death on his self primarily as enhanced self-cognition, rather than self-transformation.

Despite all their diversity, the four cases discussed thus far hence share a specific mode of biographical work. This common tendency to privilege self-cognition over self-transformation becomes all the more visible when now contrasting the above four cases with the representative of the pattern "switch". Francesco reports to have *changed* his self-definition - full stop. With regard to the thought of death, he voices precisely the same notion: that thought was intensely present only during the episode of dread described above. While he had previously denied his condition, Francesco recounts, he does not deceive himself now: "*Certainly, it is plain evident that we [people in my condition] have the sword [pending] over our head*". Yet he sees no point in dwelling on the precariousness of his life now, after that intense moment of change: rather, he wants to enjoy the improvements which that crucial experience has made possible. In short, after the thought of death "*has done its job*" (as Francesco confirms my attempt at summarizing), it has again left his mind's center stage.

In the light of the other four cases, Francesco's account is remarkable especially for what it lacks - namely an interpretation of his change of self as enhanced self-knowledge. On a first sight, this is just a natural way for Francesco to assess the effects of the thought of death on his self - after all, he has experienced a sudden shift of his old (indeed decades-old!) self-definition to its opposite. Yet, on closer consideration, his abstinence from qualifying his transformation as a progress of self-cognition does not seem to be a necessary complement of his switch of self. We can imagine, for example, that Francesco may have qualified the result of his intense dread as a revelation - the revelation of his true self as

finally liberated after decades of unease with his life as an introvert. Yet this semantics is not employed by Francesco - he simply states he changed, and that he now manages talking to others much more easily. Conversely, we can imagine that any of the above other four cases may have done without the semantics of self-cognition, and instead employ the semantics of self-transformation. Even Sergio, the champion of untainted continuity, may have said that, step by step, the lasting exposure to the thought of death has made him become strongly different from the way he used to be - and that this change would not, as far as he can tell, have come about under different circumstances. In other words: assessments of the relationship between self-knowledge and self-transformation may be analytically disconnected from the specific patterns of biographical self-construction with regard to which such assessments were made by the respondents to my inquiry.

Implications

In this paper, I have distinguished five patterns of biographical self-construction of people with HIV or AIDS, namely invalidation, reinforcement, continuity, void, and switch of self. As I have furthermore shown, this variety relies on just two different ways of assessing the impact of the intense awareness of finitude on one's present sense of self. Granted that any self-observation is by definition self-cognitive, there are two categorically distinct ways of making such observations, depending on whether or not self-knowledge takes clear precedence over self-transformation. To say "I have changed as a result of diagnosis" is different from saying: "Diagnosis has revealed my true self to me". In the first of those two statements, the present sense of self is expressly viewed as a result of the particular life-event which propelled the intense awareness of one's own finitude. In contrast, in the second statement, the self is removed into a quasi-transcendental sphere: the aspects of self which are reported to have been revealed by the awareness of finitude are supposed to exist regardless of that awareness and the event which first triggered it. While, in the first case, the present qualities of the self are conceived as hinging on specific circumstances, in the second case, changes of knowledge about the self are not deemed to bear an intrinsic relation to changes of the self. In short, the assessment of the effect of diagnosis on one's self may or may not take the form of attributing, to one's self, the status of an ultimate standard - a standard, that is to say, which is supposed to transcend empirical observability.

Among the respondents whose reports constitute the empirical basis of this inquiry, assessments of the effects of diagnosis in terms of "self-knowledge" were the rule, whereas the interpretation in terms of "self-transformation" was the exception both numerically and typologically: indeed, the latter could be observed in just one case, namely the one representative of the pattern "switch of self". In other words, the exemplary representatives of four among five possible patterns

of biographical self-construction all relied on the assumption that their self was not substantially altered by the knowledge of being HIV-positive. Given that these biographical patterns (especially the patterns invalidation and reinforcement) are crucially concerned with *changes* which came about as a result of diagnosis, this is a remarkable observation. In the late 20th century, in the absence of shared external standards which could reliably guide the process of self-constitution as mortal, there is a tendency not just of establishing self-descriptions by reference to one's own distinctive individuality (rather than, for example, a generalized moral code), but also of turning such self-descriptions into quasi-transcendental entities. Faced with the prospect of finitude, unequivocal self-descriptions seem to be needed - and the idea seems to be hard to bear that, had it not been for that nasty news ("HIV-positive"), one's self could have evolved differently. In this sense, the tendency to turn one's own self into the *apriori* of lived experience can be interpreted as a phenomenon pertaining to the cultural process which Nietzsche has termed "the death of God": by removing their own selves from the realm of contingency, contemporary individuals crave for a definite standard which, on closer scrutiny, cannot be sustained.⁹

This reasoning contains a plausible answer to my question as to the specifically modern *form* of self-constitution as mortal. Modern individuals can constitute themselves as mortal beings in a variety of ways which all rely on the establishment of their own self as a definite standard; the *effects* of the thought of finitude on the self are retrospectively bracketed by conceiving them primarily in cognitive terms, namely as an improvement of self-knowledge; the insight that one's present sense of identity is actually a result of having become intensely aware of the prospect of finitude hence becomes obscured; in short: the present

⁹ Compare aphorism 108 in Nietzsche (1887), as well as Connolly (1988: 137) and Strong (1988: ix).

sense of self is seen as a necessity. Self-transformation (i.e., a consciousness that one's present self is the *effect* of exposure to the intense thought of one's own finitude) would hence constitute a different form of self-constitution as mortal - possibly one which points beyond the horizon of classical modernity.

There is a second, more daring answer to that question; it derives from the attempt to again identify a common denominator of the semantics of self-knowledge and of self-transformation, respectively. Is it possible to infer conclusions regarding the contemporary Western *form* of self-constitution as mortal from the fact that, in my wholly unrepresentative group of respondents, the case of "switch" was the only one who abstained from applying the semantics of self-knowledge?

Self-constitution as mortal is essentially tied to biographical time. To constitute oneself as mortal means: to bring one's self-definition in tune with the prospect of scarce future lifetime. It hence does not seem arbitrary to draw attention to three variables regarding time when drawing conclusions from the empirical material generated by this research. With regard to time, the exemplary cases of the four patterns invalidation, reinforcement, continuity, and void, on one hand, distinguish themselves from the one case of switch, on the other, in three ways. First, Francesco (the exemplary case of the pattern "switch") had learned about his positive serostatus just roughly a year before the interview (the intense crisis of self-description about which he reports actually preceded the interview by a few months only); in contrast, the representatives of the other four patterns were diagnosed between three and ten years before the interview. Second, Francesco was 46 years old at the time of diagnosis, while the age of my other four exemplary cases at the time of diagnosis ranges from 20 to 23 years. This is to say, while other respondents were diagnosed during a stage of their life in which the formation of their sense of identity was still in flux, Francesco already was a mature adult at that time. Third, at the time of interview, Francesco's life-expectancy

is extraordinarily limited. While uncertainty about length of survival is a general aspect of HIV and AIDS, at the time of interview, Francesco is the only one among the five exemplary cases who has to face the prospect of possibly dying from one day to another. This minor life-expectancy is objectified by his T4-count of almost zero.

I shall like to interpret these features jointly by asking: what makes the semantics of self-knowledge dispensable for Francesco? My answer to this question is double-faced. First, the contingent nature of the event of diagnosis and, more importantly still, of that event's effects on his self, are less evident to Francesco than they are to those other respondents: due to the comparatively short time which has elapsed since his uprooting crisis, he lacks the distance which may render the observation of that contingency possible, and thus potentially make his shift of self problematic for him. Yet second, even the insight into the contingent nature of that shift may not matter to Francesco, since he has come to know all too well who he is face-to-face his death. Short of statements which would underline the cognitive dimension of his sudden change, the lesson of his recent episode of intense dread is unambiguous: he does not want to end his life as an introvert. Without any need for further consolidation by the semantics of self-knowledge, he knows *who* is going to die sooner rather than later. This certainty gives him the striking strength to now enjoy his newly acquired ability of opening up towards his social environment, rather than spending his residual time with worries about the proximity of death.

Consider, as a contrast, the exemplary cases of the other four patterns of biographical self-construction. In all those cases, the diagnosis of self had in some way interfered with the process of identity-formation throughout young adulthood - thus potentially leaving a disquieting doubt as to the validity and stability of the sense of identity which had emerged as its result. In all those cases, the manifestation of such unease is facilitated by a rather long span of time between

the diagnosis of the self, on one hand, and the self-construction established at the time of interview, on the other. The more detached a retrospective assessment is, the more easily will one observe that other developments would have been possible. Finally, all these individuals had to face uncertainty with regard to their future survival - yet in a considerably less dramatic way than Francesco. For the exemplary cases who framed the effects of diagnosis in terms of self-knowledge, it was conceivable that future life-events would again bring about considerable alterations of their self-definition. Does it make sense to assume that such uncertainty as to the *future* of one's present self-definition creates the need of enhancing its perceived stability - by retrospectively claiming its independence from any particular past event?

To be clear: I do not want to imply that self-constructions of people with HIV or AIDS will necessarily be assessed in terms of self-knowledge on the condition that those three factors converge. My intention is to find out which, if any, may be the common denominator between approaches that, at a first sight, seem to be juxtaposed to one another, namely the predominance of self-transformation as against self-knowledge and *vice versa*. According to the line of thought which I am developing here, the insight into the character of one's current self as the effect of a particular past event may become bearable on the assumption of its *future* stability - in the very precise sense of stability until the expected time of death. The need to attribute necessity to the past development of one's self would hence stem from uncertainty as to the possibility of maintaining one's present self throughout all of one's future.

Just as with the first possible answer to my question regarding the current form of self-constitution as mortal, contemporary Western individuals would thus be able to face the prospect of their own finitude "stoically", i.e. with amazing calm, on the condition that they dispose of an unambiguous and stable sense of identity. Yet differently from that first answer, the crucial test-case for that sense of self

would now be supposed to refer not to the past, but to one's future; both self-knowledge and self-transformation would be potential modalities of the modern individual's self-constitution as mortal. The re-entry¹⁰ of the past into the future could hence occur in one of two distinct modes: the semantics of self-knowledge would be a means of committing oneself to a fundamental (if at times counter-factual) continuity between past and future, whereas certainty as to one's future identity would stem precisely from the contrast between past and present when applying the semantics of self-transformation.

This second line of interpretation has a particularly explorative character. Its implications, though, merit consideration: they include a hypothesis regarding the connection between the specific attitude taken towards death in contemporary Western societies, on one hand, and modern individuality, on the other. As I have remarked in the introduction to this paper, individuals in contemporary Western societies seem to have a specific problem with the thought of death which cannot simply be deduced from institutional developments. Not only does it seem to be less necessary for modern individuals to think of their own finitude as a real problem throughout the first, say, six decades of their lives (because longevity has increased); that thought also seems to generate a historically and culturally distinctive unease.

The above line of reasoning offers an explanation. Modern society subjects individual lives to an unprecedented fragmentation and discontinuity. In both personal and professional relations, the traditional dominance of lifetime commitments has come to be largely eroded; the variety of demands made by different functional sub-systems of society on the individual impedes the formerly customary identification of self with regard to one's position in a particular family, status

¹⁰ For the definition and discussion of this concept, compare Luhmann 1984; 1987: 226 ff.; 1990; Baecker 1993.

group or hierarchy. This has meant, as I have noted previously, that the individual's biographical reflections on her or his specificity as an individual have come to assume prime relevance for the construction of a sense of identity.

Now, when reflecting on a fragmented and discontinuous life, the individual will hardly come to generate a sense of identity capable of providing a commitment for the future. Rather, the very adaptability to changing circumstances will assume crucial relevance for the way in which individuals think about their selves. This tendency of contemporary Western individuals to think of themselves as changeable with regard both to past and future has been theorized, over the past two decades, under a variety of labels such as the "mutable self" (Zurcher 1977), "biographical incrementalism" (Schimank 1985), and the "protean self" (Lifton 1993). This literature grasps a relevant aspect of the conditions under which contemporary Western individuals are held to define themselves. The potential future reversibility of one's current self-definition has become part of the contemporary self's reflexive project. I assume that this is why the "taboo" of death could be observed at all: The current systemic pressure for individuals to keep their self-descriptions in a somewhat liquid state bears an at best ambivalent relationship to the thought of finitude. The intense awareness of one's own mortality is at odds with the provisional self-definitions required from contemporary individuals in order to function in a diversified and changing world.

I hence suggest that the central issue for understanding modern individuals' capability of facing finitude be their relation toward contingency. This argument has a Weberian genealogy: the more manifold and differentiated the society in which one lives, the less likely is it that one's death will be experienced as meaningful (Weber 1920a: 569 f.). The conviction to have rendered one crucial aspect of self stable, and hence reliable, up to the time of death may be the one way out for us modern individuals to bear the dramatic contrast between the immense va-

riety of options for further activity and self-fulfillment, on one hand, and the finite character of our existence, on the other. There is a relevant practical implication to this consideration: the difficulties encountered by the HIV-positive in their attempt to render the thought of death compatible with their lives and selves are not to be understood in psychiatric, but in cultural terms; they highlight the more general difficulty encountered by contemporary Western individuals in their effort of coping with a world where previously incontestable external reference-points have become obvious as contingent constructs.

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