

## "Life in Brackets": Biographical Uncertainties of HIV-Positive Women in South Africa

*Marian Burchardt*

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**Abstract:** As South Africa is witnessing a maturing AIDS epidemic, the experience and impact of the disease are written ever more firmly into the biographical self-constructions of the infected. In this article, I explore typical strategies of dealing with uncertainties arising from new challenges, after the shock of ontological insecurity ensuing from the diagnosis, has been overcome. The analysis is based on contrasting interpretations of problem-centered biographical interviews with HIV-positive South African women. In the process, results have been formulated in terms of hypotheses regarding links between biographical situatedness and strategies of action. The hypotheses have been validated through case comparisons. The article highlights personal transformation, social support and the search for normality as key aspects for understanding these strategies and spells out how these are enabled, constrained and shaped within the social domains of religion, AIDS activism and township youth culture.

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### 1. Introduction

About 20 years ago, Nelson Mandela's release from political imprisonment and the final collapse of the late colonial power apparatuses of the apartheid state signaled a new dawn for the country at the Cape; South Africa celebrated the coming of the "rainbow nation" while Mandela's personal history on his "Long Walk to Freedom" became one of the world's most read autobiographical accounts. It is one of the sad facts about the country's current predicament that the notion of biography, of narrated and written life, has meanwhile become almost synonymous with an account on life with HIV/AIDS. In a society with roughly 5,5 million infected people, where one in five adults is HIV-positive, the experience of stigmatized disease has been forcefully inscribed into individual and collective histories, either through the pain of infection, or through the fact of

loss and the witnessing of other's suffering on the part of the bereaved. Often AIDS affects entire families: because both parents and children are infected, because infected mothers are incapacitated to care for their children, or because sick fathers are unable to continue acting as breadwinners for their families. [1]

Not a long time ago, however, those who were able to narrate "life with AIDS" simply because they managed to survive into mid- or long-term HIV-positivity were a rather privileged minority. HIV-infection was, in fact, as has often been stated a death sentence. This situation is changing dramatically as the improvement of, and increased access to, anti-retroviral medicines (ARVs) is turning AIDS from a death sentence into a chronic disease for growing numbers of South Africans. As a result, not only the individual experiences but the public image of AIDS is undergoing rapid transformation. As long-term survival is becoming a more common phenomenon, so are biographies of people infected, people alive and kicking instead of sluggish and dying. Thus AIDS biographies may be written much more firmly into cultural discourse than ever before. [2]

Yet the situation is more complex. As people overcome the almost invariably traumatic experience of diagnosis and possibly ensuing and recurrent periods of illness, other concerns may return to the fore. For the majority of the infected, life is characterized by poverty, the daily struggle for survival, and the need to seize the tiniest opportunity to generate income wherever it emerges (GILBERT & WALKER, 2002). Under these circumstances, the possibility of developing "full-blown AIDS" may well be perceived as just one amongst numerous sources of uncertainty; hence the need for contextualizing and historicizing the experience of AIDS within sociological accounts. Moreover, whether AIDS figures in biographical accounts or not is closely linked to how people engage with dominant cultural stereotypes and their inherent moralizing implications on multiple levels. Studies on how cultures of stigma and silence have worked to erase AIDS from individual self-representation and everyday discourse alike abound (BURCHARDT, 2007a; DELIUS & GLASER, 2005). But as Jean COMAROFF also reminds us,

"(...) the inaudibility of talk about AIDS is often less a matter of brute repression or secrecy than of complicated communicative practices in the context of radical uncertainty. (...) maintaining the ambiguity about one's status, or the presence or absence of the disease, can be an act of self-presentation, defiance, or resignation in the face of an apparently implacable fate" (2007, pp.202-203). [3]

This article engages with the fact that uncertainty not only operates when talk on AIDS is muted but that it is also accessible when AIDS is being talked about, namely in biographical accounts; it is one of the major forces affecting the biographical projecting. Claiming that biographical approaches provide supreme access to the experiences of HIV-positive people in their social making, I wish to highlight three aspects that I see as central to their ways of dealing with biographical uncertainties: personal transformation; support; and imaginations of

normality.<sup>1</sup> Drawing on the cases of three young women from the South African city of Cape Town, I explain how uncertainties ensuing from the experience of diagnosis are reflected on the level of individual biographical perspectives.<sup>2</sup> Thereby I also explore how the meanings of uncertainty are inscribed into the complex and diverse strategies people employ in navigating their quotidian orientations. [4]

I begin by assembling key aspects for the sociological analysis of biographical uncertainties and AIDS as they take shape in contemporary South Africa. In a second step, I consider emerging notions of autobiographical narratives in the political context of the post-apartheid era. The final part of the paper is dedicated to the presentation of three cases, each of which foregrounds a central dimension to the experience of, and forms of dealing with, biographical uncertainty. [5]

## **2. "Mending the Narrative Tear"? Biographical Approaches to AIDS, Time and Uncertainty**

The diagnosis of terminal disease has a unique status within individual biographies and must be construed as an extreme case among the life events that generate biographical uncertainty. The sociological notion of biographical uncertainty points to the weakening or dissolution of standardized expectations, and to the very "expect-ability" of life developments as outcomes of actions against the backdrop of a given social situation in time.<sup>3</sup> With the diagnosis, the perspective on the future is doomed to shrink. According to most studies, particularly during the first phase of confronting the diagnosis, people inevitably find themselves thrown into a precarious and emotionally painful present in which the subjective uncertainty even about short-term survival is radically disrupting all connections to an envisaged future. Moreover, the diagnosis disconnects people from their past in that formerly held assumptions about life are no longer tenable while the sense of self with any degree of coherence is—in this moment—lost. [6]

Perceptions of biographical uncertainties are, however, anything but static and change over time. The initial shock of diagnosis is typically followed by questions such as: "Why me?" "Will I still be alive tomorrow?" The experience of day-to-day survival later gradually gives way to a more active confrontation with the new life circumstances and involves an incipient differentiation of the temporalities of life, i.e. of linkages between past experiences, present existence and future expectations. In South Africa, the way uncertainties are further articulated is closely related to the biographical situation of the age group within which the majority of infections take place, people between 15 and 35: Will I be able to find a husband or a wife, or will my husband or wife stay with me? Will I be able to

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1 In terms of data collection my analysis is based on biographical problem-centered interviews with a thematic focus on experiences and strategies of dealing with HIV/AIDS. On problem-centered interviews see WITZEL (2000).

2 For a detailed discussion of the relationships between gender and AIDS in South Africa, see BURCHARDT (2007a) and LECLERC-MADLALA (2001).

3 For an excellent account on the intrinsic connections between the concepts of time and biographical uncertainty see REITER (2007).

have children, sustain myself economically or mobilize support from family, friends and the community when falling ill? What kinds of health-related practices should I adopt in order stay healthy? [7]

The first study on AIDS employing the perspective of uncertainty dates back to 1989 when ROSE WEITZ interviewed 25 HIV-positive people from Arizona (USA), focusing on how they sought control over their lives by finding satisfactory cognitive explanations for their disease. Building on earlier findings from medical sociology according to which uncertainty is a critical issue for chronically and terminally ill persons and a major source of stress, she maintained that "it is this sense of control which enables people to tolerate uncertainty" (WEITZ, 1989, p.271). Many of the questions she identified as central to her respondents' lives such as "Will I develop AIDS?," "What do my symptoms mean?," "Why have I become ill?" or "Will I be able to live and die in dignity?" have lost nothing of their significance and are equally pertinent to the South African case. One of the shortcomings of her approach, however, is the assumption that people inevitably seek to reduce uncertainty, for example by gathering scientific information (ibid., p.270). On the basis of my own findings, I would argue that particularly in the absence of a cure, the prospect of death renders some degree of uncertainty about when death is due in fact highly desirable. [8]

In a remarkable study carried out in the UK, DAVIES (1997) added an explicit focus on the relationship of time to the experience of HIV/AIDS, asking how the shattering of routine temporal orientations, that diagnosis and possible acute illness entail, affects people's sense of ontological security and being "in time." Importantly, she stresses

"(...) that a characteristic feature of the individual who has been living with an HIV positive diagnosis for a substantial period of time is that the imminent possibility of death is supplemented with the possibility that death may not be as imminent or as inevitable as it at first seemed" (ibid., p.565). [9]

As an outcome of her analysis, she identified in an ideal-typical fashion three temporal orientations, namely "living with a philosophy of the present," "living in the future," and "living in the empty present." Characteristic of the first type is the highly positive evaluation of a focus on the present, the idea of having grown spiritually by a renewed appreciation of the value of life in its daily unfolding after the diagnosis, as well as a certain sense of liberation from the social pressures to permanently focus on achieving individual success in the future. Individuals of type 2 (future orientation) achieved the reconstitution of an open biographical horizon through virtually denying that they were infected. Those "living in the empty present," on the contrary, "over-accepted" the reality of diagnosis in that the focus on the terminal character of the disease precipitated their progressive detachment or disengagement from the present individual and social realities of life as such. Unfortunately, the absence of a more explicit biographical approach foreclosed the opportunity to analyze how this oscillating between acceptance and denial is biographically shaped, that is, how underlying and resulting uncertainties are intertwined with past patterns of experience. [10]

These shortcomings are eventually resolved by SOKOLNE's (2003) perceptive analysis of life stories of HIV-positive women from Cape Town/South Africa. She mainly draws on narrative theory and the idea "that chronic illness, such as HIV/AIDS, signifies a juncture or disruption in the life narrative, whereby the sense of temporal connection, and relatedly purpose and meaning, is lost" (ibid., p.6). On the basis of this assumption, she draws attention to the multiple ways whereby these women are trying to mend the narrative tear inflicted by the HIV-positive diagnosis. It is precisely the biographical focus of SOKOLNE's work that allows her to recognize "(...) that, while an HIV-positive diagnosis is likely to be traumatic in itself, it potentially re-evokes past traumas and losses, intensifying pain (...) where the struggle is (...) to also come to terms with experiences that originate in the past" (ibid., p.23). However, I suggest that departing from a notion of uncertainty rather than trauma has conceptual advantages, namely the fact of pointing to the productive dimensions of loss and contingency. [11]

### **3. The Making of Biographies in Post-Apartheid South Africa**

It is important to remember that biographies as socially available forms of constructions of the self are not given per se. They emerge and take shape through history. In South Africa, biographical accounts have been imbued with particular prominence after the end of apartheid as forms of remembrance and bearing witness to the past, namely in the process of national reconciliation and its institutionalization through the Truth and Reconciliation Commission (TRC). In this context, they have morphed into instruments of public testimony, into forms of articulation linking the self with the politics of history, and individual suffering with political violence. COLVIN (2005) has perceptively demonstrated how "traumatic storytelling" became a micro-political means for individual and national healing, remembrance, and not least for making claims to the recognition of victimhood. Facilitated by an emerging political rhetoric on the past, characterized by notions of "national catharsis," these practices of memory later dispersed across the South African social landscape and continued their social life even when the TRC had come to an end. What matters here is that in the process, through their incorporation into public testimonies, biographical accounts assumed a specifically scripted form. As modes of both therapeutic introspection and political self-identification, biographies had been molded into a genre of dramatic narration. [12]

Once crafted and socially available, this genre was later readily adopted by AIDS activists in an attempt to publicly speak out about their experiences when denialism reigned supreme (FASSIN, 2007). Scholars such as ROBINS (2004) have noted that the ritually staged performance of illness testimonials is indeed a central element within the cultural repertoire of the South African AIDS movement, especially in the political activism led by the Treatment Action Campaign (TAC). During my field research I came across these performances in countless instances during support group meetings, counseling sessions, public campaigns and private gatherings. Invariably, delivering autobiographical accounts became Freudian acts of "working through," invested with therapeutic

significance, and often politically charged practices making claims to "therapeutic citizenship" (NGUYEN, 2005) and symbolic inclusion. [13]

This has important methodological implications for it reminds us of the constructivist claim that biographies are first and foremost linguistic styles and strategies. They are mechanisms for the representation of meaning with built-in tendencies to obscure the social reality behind them as the very production site of meaning. If biographical research wants to go beyond the mere analysis of genres of speech and narration however, if it claims to retain the connections between representation and social reality, we need to pay attention to the selectivity of what is addressed, forgotten or denied (WOHLRAB-SAHR, 1999a). What matters is how the dynamics of narrating in the research situation reproduce the cognitive forms of understanding that also shaped experiences in the past. Particularly by shedding light on the interstices of narration in which people are entangled into the dynamics of experience, we may indeed retain access to the social reality shaping biographical projecting in the face of uncertainty in time. [14]

Within the perspective employed here, however, access to social reality is not granted by reconstructing the subjective meanings people attach to their practices and statements. It rather emerges from confronting *what is said* with *what is done*, from analyzing how subjective meanings are linked to objectified expressive forms and objective problems of practice. In this sense, my analysis closely follows WOHLRAB-SAHR's (1999b) suggestions regarding the use of structural hermeneutics for investigating biographical uncertainties. What is in question then is *how typical actualized strategies of dealing with biographical uncertainty as the overriding problem of practice relate to the biographical shaping of typical structural situations*. Consequently, the hypotheses I am presenting refer to designated sets of situations with structural commonalities rather than designated groups of individuals. "Personal transformation" for instance, is a creative adaptation whereby breaking with the past is rendered a condition for retrieving the future, which may hold for HIV-positive people but also for people with other, structurally similar figurations of uncertainty. The hypotheses have been generated through the interpretation of autobiographical accounts of HIV-positive South Africans. In their abstract formulation as *concepts* as well as in terms of sampling they are a result of minimal and maximal contrasting (WOHLRAB-SAHR & PRZYBORSKI, 2008, p.239). In this sense, the following analysis lays claims to theoretical saturation as spelled out in the grounded theory approach (see STRAUSS, 1991, p.21). [15]

As mentioned above, the diagnosis of HIV-positivity is typically an experience of radical discontinuity. After the initial shock, people are challenged to adapt to their new physiological condition and its social implications on multiple levels. Disclosure to family and friends, securing economic livelihoods, choosing forms of medication, and coming to terms with infection in the domain of intimate partnerships are just some of the areas in which uncertainties surface. Changing one's life seems inevitable and the sociological question is, in which forms these changes play themselves out. What is in question here are processes of *personal transformation* that highlight relationships to time and self. Whether they take

place or not, and specifically the shape they take, in turn depends on the social support people receive or manage to mobilize. In other words: In order to theorize the social situatedness of AIDS biographies we need to unpack the contingency of moments of *support* that have shaped it. Conceptually speaking, support and care concern relationships to the social environment. While all of this points to the social discontinuity and asymmetry between the lives of HIV-positive people and the social world surrounding them, people may well desire to re-situate themselves in "normal social life," "dis-identify" from AIDS, and search for continuity with the past. They may even reject emotional and practical support since it asymmetrically posits the HIV-positive person as an object of compassion. In this sense, the *longing for normality* speaks to the concerns with otherness. In the following, I will elucidate the concepts of transformation, support and longing for normality as three constitutive aspects of dealing with biographical uncertainty. By reconstructing autobiographical accounts of three women I seek to uncover their structural impact on the production of the women's accounts. [16]

#### **4. Living with Uncertainty: Transformation, Support and the Search for Normality**

##### **4.1 "Completely breaking with the past"? Healing through conversion<sup>4</sup>**

Maggie is a 36 year old woman working for the faith-based organization "Living Hope Community Centre" (LHCC) who is running AIDS projects and other welfare programs for communities in the Southern suburbs of Cape Town. When I asked her to relate her life story, she responded: "Do you want the long or the short version?" The answer and the following account revealed that she had already shared her story with others on many occasions, mostly in the context of her work. Although I had replied that I would be interested in the long version she first responded by delivering the short account while only elaborating on it in detail after my intervention. The short account, however, already entailed the life events most relevant to her in a nutshell: being diagnosed HIV-positive; being saved from the spell of disease by conversion to Pentecostal Christianity; and pursuing her goals in life independent of the restrictions her disease might impose upon her through the help of religious faith. All other elaborations, it seems, are somehow organized around these narrative nodes. [17]

She was born in the small town of Butterworth in the Eastern Cape province and grew up with relatively little in the way of parental control. When the racial system of apartheid was overthrown she was about 20 years old; the experience of freedom and "being crazy about life" in this period seemed to be a combined outcome of joy over the newly won liberties and a general sense of youthful happiness. And yet ambivalences in the perspective on the past generated by the conversion to Pentecostalism are already evident: "We were doing things that were not suitable for life," she recalled. "It was really bad (...). It was just partying. We just had a really good time." [18]

<sup>4</sup> The notion of *completely breaking with the past* is adapted from Birgit MEYER's research on practices of conversion and relationships to time in Ghanaian Pentecostalism (MEYER, 1998).

The time of "care-less youth" was soon to come to an abrupt end when she became pregnant for the first time at the age of 23. Although the pregnancy came as an utter surprise, she was prepared to raise the child alone with the help of her mother and immediately foreclosed the idea of marriage with the child's father. She acknowledged that the relationship did not reflect deep personal commitment. The fact that babies were born even in such a liquid intimate connection seemed perfectly acceptable to her. This acceptance appears to rest, firstly on the responsibility and willingness of the maternal family to take over the work of childrearing; and secondly, on a weak notion of fatherhood based on the expected provision of material resources and comparatively loose emotional ties. The father's lack of care for the baby and the refusal of material support, however, left her strongly disappointed. Fortunately, her mother's support in raising her daughter allowed her to complete her secondary education. Yet after a whole year of looking for a job in her native town without success she saw no other option than to move to Cape Town, leaving her child behind with her mother. [19]

At the arrival to Cape Town, she first moved in to live with an aunt. Soon after and through contacts she made in her church she started working at an orphanage run by the international NGO "SOS children's home." She kept on working there for about eight years. In the meantime her father passed away. "And then," she continued, "I met this guy and we fell in love. And I ended up pregnant again in 2002." He became her boyfriend and the relationship was consolidated. [20]

Like many other South African women, Maggie was tested for HIV in the context of the antenatal exams during her pregnancy. Not surprisingly, the diagnosis of being HIV-positive came as an extreme shock. The first thought she had, was simply: "This is the end of my life." Through the experience of diagnosis death invades life. Her feelings of frustration were exacerbated when the doctor told her about the risks of mother-to-child-transmission. In addition, she had to change her job as employees in the orphanage were not supposed to have children. In that situation, she concluded "I didn't know what to do with my life anymore" and decided to have an abortion. For reasons she did not elaborate on she later changed that decision and chose to keep the child. [21]

In the following period, she was channeled into psychological recovery projects and participated in the meetings of an AIDS support group. Seeing people coping with HIV in a positive way and identifying with them by finding out "we are the same" she perceived as utterly important in moving out of her depression.<sup>5</sup> As an outcome of participating in these care programs her emotional situation gradually stabilized. In medical terms as well, her situation appeared increasingly positive. Her CD4-count, the medical parameter defining the strength of the immune system, moved up and in general she was satisfied with the treatment and medical services she had access to on the basis of her health insurance. Despite some second thoughts she agreed to enroll on an ARV treatment therapy and her

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5 On forms of collective solidarity and support in response to AIDS, see BURCHARDT (2007b).

second child was born in a healthy state. Besides, after the delivery she moved in with the father. [22]

In this situation, however, she gradually began distancing herself from her past, a process that eventually culminated in the act of religious conversion. After one and a half years of cohabitation she started feeling uncomfortable and decided to move out while still maintaining the relationship. In the first place, the choice to move out was motivated by issues over the organization of everyday life. Yet on another level, this illegitimate cohabitation already signaled much what of she later perceived as essentially un-Christian. Moving out from the common flat should therefore be interpreted as a first act of spatially and socially distancing herself from the world she used to inhabit. [23]

About three years ago, soon after moving out from her boyfriend's place, a friend took her to an Evangelical crusade. This is where, as she put it, "she found God." What followed was a process of acting out her religious conversion, which provided her with an elaborated web of categories through which to understand and act upon herself: "My life totally changed. I began loving and accepting myself. I grew spiritually. I didn't know anything about my life but now I know. Jesus admonished me and I changed my whole lifestyle." Some of the most important of the lifestyle changes she made concerned her relationships to men, her views of sexuality and her gender identity. Immediately after her conversion, she decided to leave her partner. In this context, she explicitly stressed that the reason for breaking up with him was not that she did not love him anymore. "I just left him after I converted," she recalled indicating that her reasons for quitting were essentially external to the relationship itself. What is more, she eventually came to opt for a lifestyle of total sexual abstinence. Asked whether she would be interested in marrying she stated:

"Now I don't even care about guys anymore and Jesus is helping me everyday. (...) But because I am a born again child I am saved, I am a child of God. So I don't even care, I don't even think about marriage. I am only focusing on my life in Jesus. That's it. As long as I am getting in my promised land, that is all that concerns me. Marriage will come if God wants it. I don't think about it." [24]

What we find here is indeed a narrative of radical disjuncture. It seems that the belief in being saved and thus not "having to care" she perceived as an experience of liberation. Yet what precisely is it that she does not care about when saying she does not care about guys anymore? We may suggest that it is the whole drama of intimate female-male interaction, especially of achieving personal fulfillment in them, and of finding help in a partnership that is much more reliably provided by Jesus Christ. The conversion to Pentecostal Christianity literally eliminated all these concerns and substituted them with a single destiny, i.e. to focus on her faith in Jesus. This argument is consistent with the findings of other studies into the gender dynamics of Pentecostal Christianity in Africa and Latin America, which point out that conversion often comes to signify a process of purification in which relations to men are symbolically replaced by the relationship to Jesus Christ. [25]

This raises the question whether it was the dissatisfaction with her partner, or with men in general, that pointed to the benefits of conversion in this regard, or whether it was rather the religious conversion that imposed a different set of interpretative categories and moral norms with regard to interaction with men. The question is difficult to answer. It seems to me that both the abandoning of intimate relationships and the religious conversion are mutually entangled in terms of cumulative evidence; both are parts of one more encompassing process of distancing herself from the past. This process had already begun well before her religious conversion. She recounted that through some medical inquiries she did following the diagnosis, she found out that abstaining from sexual intercourse would also be beneficial for her health status.<sup>6</sup> As a consequence, she already stopped having sex right after the diagnosis. Thus we could argue that the religious conversion also ratified an ongoing process of personal transformation rather than ritually initiating it, while certainly bestowing the practice of sexual abstinence with new personal meaning. [26]

Eventually, the conversion had profound implications on the way she deals with her HIV-infection. The following passage illustrates how her understanding of HIV was affected by that process:

"Doctors are not God, they just give you result of scientific exam but that's a lie. They tell you, you are gonna die. But you are still alive. They are not God. So why should I bother? They just use their machines. You never know, today CD4-count is low, maybe tomorrow it is up again. I was well treated but it is my understanding. You don't know what God is doing overnight. HIV doesn't exist in my blood. That is what I believe." [27]

Maggie firmly believed that her life was eventually in the hands of God and took the changing results of medical tests as evidence for that. The conversion, it appears, confirmed her profound mistrust of medical definitions of HIV/AIDS, a development that is also reflected in the fact that she stopped taking anti-retroviral drugs in spite of receiving them free of charge through her health insurance. She symbolically removed her body from the medical machineries to put it in the hands of God. And in this act we find a striking analogy to the way she removed herself from men to dedicate her life to Jesus Christ. The faith in biomedicine is replaced by the faith in God. Again pointing to the link between her religiosity and her disease she explained:

"I got spiritual healing and I could feel that I am healed. So for me HIV is not in my mind, it is not in my brain, because I understand that I am healed and I believe that I am healed through Jesus Christ." [28]

In Pentecostal Christianity the notion of spiritual healing is often an intrinsic element of conversion and of being saved, and in some contexts all of these ritual practices acquire almost synonymous meanings. Spiritual healing is a practice

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6 Having unprotected sexual intercourse when being HIV-positive carries the risk of so-called super-infection and thus of increasing the viral load of the blood. It seems plausible that in the given context Maggie was referring to this theory.

that typically denotes the ritual treatment of afflictions ranging from spirit possession and disturbed kin and other social relations to physical ailments such as barrenness and impotence. It is thus often used for addressing concerns about endangered social reproduction and a wider understanding of social and cultural suffering. Against this backdrop, Maggie's remark strikingly captures how this notion can be employed in the context of HIV/AIDS, in other words: how the selective appropriation of elements from the available repertoire of religious vocabularies helped her in dealing with her disease. While in a former comment she had claimed that Jesus had literally removed the virus from her blood, in the sequence above she draws attention to how spiritual healing was helpful in removing HIV from her thoughts. HIV-infection thus emerges as a psychological disease, as an affliction that impairs life by constantly reminding the infected person of possible future suffering, the corresponding breakdown of life routines and impending death. Thus, it is also these mental impairments that are remedied by the spiritual healing she received. In this sense, "healing through conversion" should be understood both as a ritual passage linked to critical biographical experience and as a practice of care that is in some sociological proximity to notions of psychotherapy (BURCHARDT, 2009). At once we find here a form of self-care that allows her, as she put it, "not to care" because much of the contingencies of life with HIV are bracketed in the phenomenological sense through religious conversion. [29]

#### **4.2 From patient to expert: A life for AIDS activism**

Like Maggie, Palesa comes from the Eastern Cape where she was born in 1988. Her mother was raised in abject poverty in which the struggle to make ends meet and survive was the reality of everyday life. Her maternal grandmother died when her mother was just six months old, and since her grandfather was sick too, her mother became the family's breadwinner when still a child, rendering school attendance thoroughly impossible. Out of utmost desperation, in 1990 her mother decided to move to Cape Town in search for a better life, or perhaps just in a promising attempt of making sure she and Palesa, her youngest child, had enough to eat. Palesa's two older brothers and one older sister remained with relatives in the Eastern Cape. However, the promises were not fulfilled. The family barely got by. For years, they lived on the mercy of others, staying in some resident's backyard shack for a couple of months before they had to move on in search of yet another temporary home. Moreover, things got worse when her mother fell ill with some mental disorder which incapacitated her and prevented her from being able to work. The family ate from the dustbins of the poor while Palesa, then about five years old, tried to generate some income by selling sweets and candy on the roadside. Recalling these life circumstances, at some point she concluded that it was for their best that her older siblings disappeared from her life. It seems clear that her mother was just too willing to accept that they would seek a better life independent from her, for she could offer nothing but misery. [30]

Towards the end of the 90s, however, Palesa's and her mother's life circumstances improved considerably. On the basis of her disease, her mother

was awarded a disability grant as well as a tiny matchbox-style house—one room plus kitchen—in the poor but increasingly formalized settlement of Makhaya. At the age of 13 Palesa fell in love with a pastor's son. To her mother, however, this relationship was unacceptable. Instead of seeing the relationship to him consolidated as Palesa wished, she was sent by her mother to stay with some distant relatives in Crossroads.<sup>7</sup> As an active member of a Pentecostal congregation, the idea of her daughter dating a pastor's son seemed to threaten the mother's reputation in the church community, which had meanwhile become a place of solace and her primary social network. Yet living in another township not only separated Palesa from her former lover; it also separated her from maternal control. In Crossroads, just about one year later Palesa made the acquaintance of a 27 year old man; she fell in love again and started another couple relationship. Roughly two years later and without ever having heard about condoms or contraception she became pregnant by the end of 2002. At the clinic, the nurses routinely informed her about the necessity of taking an HIV-test in order to avoid a possible sero-positivity of her daughter through mother-to-child-transmission. She easily agreed, for because of her faithfulness she was fully certain the test-result would be negative. When she found out she was HIV-positive, realities crumbled. [31]

At first, Palesa hesitated to disclose to her mother out of fear of negative reactions. She decided to tell her best friend instead who went to talk to the mother. Contrary to her expectations, however, her mother turned out to be fully supportive. What is more, in the midst of the ensuing biographical crisis—facing the double burden of teenage motherhood and terminal disease—the parental bond was vigorously reinforced. Palesa returned to the maternal home while similar to Maggie's experience, the father of the child refused to adopt parental responsibilities and "fled" to the city of East London, about 1000 km away from Cape Town. Her mother, however, gave her emotional support and took over much of the childrearing responsibilities, thereby allowing Palesa to pursue various kinds of AIDS-related activities in the context of local civil society activism, which later moved center-stage in her new life-project. [32]

Before the birth of her daughter, the nurses at the clinic recommended that she join a support group for HIV-positive pregnant mothers, the so-called mother-to-child-transmission support group. She decided to attend, thereby initiating her engagement in the field of AIDS activism. In course of the years to come she visited several such groups on a regular basis and gradually transformed from a "client" into an "AIDS expert," a social passage that is actually crucial for understanding South African AIDS movement politics as a whole (ROBINS, 2006). [33]

In the course of her medical examinations, it soon became clear that it would be physiologically beneficial to enroll on an anti-retroviral treatment regime. At the time, however, access to these expensive medicines through the public health sector was still extremely limited. She was therefore advised in the support group

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<sup>7</sup> Crossroads is another township, located between the bigger urban agglomeration of Khayelitsha and the city proper.

to join TAC which facilitated access to these drugs through their cooperation with Medicine Sans Frontiere (MSF) and already ran an ARV-rollout pilot project in the township of Khayelitsha (ROBINS, 2004). In the support group, she recalled, it was common to suggest that joining TAC would be helpful in many ways while it was not quite clear how—apart from facilitating access to life-saving drugs. At TAC, she found out that apart from organizing the political struggle against the government and the pharmaceutical industry for the free and universal provision of drugs, the organization effectively serves to disseminate the latest medical expertise on HIV/AIDS amongst its members. Indeed, TAC can be regarded as the single most important institutional actor pushing the frontiers of "lay-expertification," giving people vital information on how to successfully live with HIV or AIDS on treatment. [34]

In the context of her engagement with TAC, Palesa participated in various training courses such as "treatment literacy training" and media peer education training. After concluding the treatment training, she knew all the technical and medical details of AIDS drugs, such as chemical components, possible side-effects and how to deal with them etc. The medical consultations with the physicians of MSF on "treatment adherence" only revealed that she has already turned into a "doctor of herself" (FOUCAULT, 1988, p.31). Later she became a peer educator, contributing to the production of educational programs at local radio and TV stations. Parallel to that, she ran a teenage mothers' support group, facilitating training in basic income generating activities such as sewing, beadwork and the usage of computers. After six more months she embarked on yet another project when she began volunteering as a peer educator in the youth clinic of Khayelitsha. From Monday to Friday she is counseling youth clients on HIV, sexually transmitted diseases, and family planning while Saturdays are typically reserved for TAC-related activism. [35]

Through her TAC activism, Palesa became a committed proponent of ARV treatment. Given the widespread epistemological uncertainty about HIV treatment possibilities this can indeed be viewed as a major personal achievement. For years South Africans have been exposed to highly contradictory messages regarding therapeutic options. TAC's ARV campaigns, the vitamin cocktails advertised by the dubious Dr Rath Foundation, the government-sponsored "African diet" (consisting of beetroot, garlic and the African potato) and the various paradigms of faith healing and herbalist treatment are just the most salient examples within a cultural framework of entrenched medical pluralism. These issues were rendered major points of confrontation within her church community. [36]

While overall churches—after an initial period of stigmatization—have become important resources of support for AIDS sufferers (BURCHARDT, 2007a), things proved highly difficult in the Pentecostal "Gospel Church of Power" she had been visiting together with her mother for her entire life. After disclosing her HIV-status to her pastor, she was asked to sit on a separate bench especially designated for HIV-positive people. According to the official teaching of the church, HIV is a demon that may solely be vanquished by the healing force of prayer, especially

the prayer of the pastor, and the healing touch of his hand (on ritual AIDS healing in Tanzania see DILGER, 2007). The healing ritual concluded in that "they are forcing the people to go and stand and say, "before I came here I was HIV-positive but my pastor prayed for me and now I am HIV-negative," as Palesa explained. Quite obviously, this understanding and healing paradigm stand in an irreconcilable contradiction to the expertise Palesa had acquired through her TAC activism. For the church, the contradiction was resolved in that no HIV-positive person was permitted membership who did not abjure any other kind of treatment, both biomedical and "traditional"; for in the eyes of the pastor engaging in alternative therapies would testify to the lack of belief in the healing power of the holy spirit. After a furious debate with the elders, Palesa left the church once and forever. [37]

In late 2003, shortly after that incident, she visited a support group meeting where she got to know Meliziswe, a local faith-inspired AIDS activist. As a first result of this meeting, he introduced her to his own church congregation called "El Shaddai," in which he had already indoctrinated a "progressive" attitude to AIDS in his capacity as a lay-preacher. Palesa joined "El Shaddai," and although condoms and sexuality are non-issues within church discourse, she felt welcome and relieved for having escaped the overt stigmatization and (what she perceives as) medical charlatanism in her former church. Meliziswe and Palesa formed a close friendship based on their common commitment to AIDS activism. After one of the AIDS awareness raising and education workshops Meliziswe was regularly organizing in a small community hall in Khayelitsha, they discussed opportunities for further projects. Eventually they decided to form a support group themselves. [38]

With regard to ways of dealing with uncertainty, one major difference to the case of Maggie is that in her experience uncertainty is much more closely related to instable material life circumstances. Making ends meet is permanently difficult and the question of how to sustain herself, her daughter and also her mother—in spite of the improved situation through her welfare grant—remains a constant challenge. As a consequence, her life trajectory following her infection is shaped to a much greater extent by available support structures. Palesa's case reveals how the existence of these support structures and their skilled use by individuals conjoin in organizing a chain of *progressive social re-inclusion*. Through, and as a result of, that process two major transformations can be observed: First, after an initial phase of rather passively receiving support in the form of advice in institutional contexts, she moved on to actively shape her own support networks. This is particularly evident in the way she strategically chose her religious community according to the attitudes of the congregation. The second transformation relates to the ways in which she moved from being a *receiver* of care to *providing support* herself. Palesa is indeed a typical example of how HIV-infected people and AIDS sufferers in South Africa skilled and "expertified" themselves, thereby transforming themselves into leading AIDS activists and their illness experience into a vocation. [39]

### **4.3 Painful remembrances: Sexual violence, AIDS and the longing for normality**

At the time of the interview, Thembisa was 22 years old. Her account begins with a short description of her family background. Just as the other two women, she was born in the Eastern Cape Province where she reportedly lived with all kinds of relatives. When she was eight years old she and her mother moved to Cape Town where they lived together with her mother's new husband and her younger brother in a small backyard shack in the township of Gugulethu. At the time, her father was working at some industrial plant while her mother seized the opportunity to work as a nurse at the local clinic. This sudden absence of parental care Thembisa dramatically construed as the moment "in which the problem started." A man from the neighborhood was supposed to take care of her and another few children. For more than two years the very same "caretaker" repeatedly sexually abused her, thereby initiating Thembisa into a life marked by abuse, violence and coercion. [40]

This history of violence and abuse, however, pertains to the dark side of her life; as much as—in and through delivering her autobiographical account—she could not but constantly drag these dark events from her subjective experience into the light of narrative representation. However, she took pains to present herself as someone who has been and is actually living a normal social life. In this sense, she was quick to add: "But in short, I grew up like any other kid." Up to this point one could hypothesize that what is at the bottom of this statement is a broader notion of childhood social suffering, or else the idea that all children undergo experiences of abuse in one way or another. Yet it seems that to understand her account we should construe such suggestions of normalcy as introducing a fundamental distinction between what is visible and what remains hidden; between what one discloses to others and what therefore constitutes the elements interwoven into one's social identity on the one hand, and what remains within the confines of subjective experience on the other. These latter aspects were then, as she observed, what she was trying to deal with by "wiping it out of my mind." I would argue that relating a biography replete with utterly dire experiences as if it were a normal one and constantly attempting to locate herself with the terrain of normality is constitutive of Thembisa's way of dealing with uncertainty that is endemic to her biographical experience. [41]

As a teenager "growing up like any other kid" meant that in her view in order "to get by" one had to choose among a limited number of alternative pathways:

"And well, to live in an area where I live, you have to (...), it's either you get yourself into a church, get yourself a very well-known boyfriend, or get yourself a gangster. There're three options. You get yourself an ordinary guy and he's gonna end up dead or something. So I got myself this well-known gangster. But I didn't know at the moment actually." [42]

Ensuing from there is a life story that revolves around profoundly disturbing relationships with men. At the age of fourteen she started dating "this well-know

gangster." This relationship she perceived as essentially *formative* for years of her life to come: He introduced her to alcohol and drugs; he taught her how to use guns; and eventually she insisted that it was him who taught her "everything I know." After two years, her boyfriend was shot dead in one of the township taverns in an act of revenge for some murder he had committed shortly before. Instead of being repelled by this event, or encouraged to change her social milieu, she was suddenly afforded some kind of fame out of *having survived* in the eyes of the township youth. Her life became ever more excessive and I could certainly sense some degree of pride in her when she related how even after a series of consecutive nights of parties she would invariably prevail in brandy drinking competitions with any of her male peers. [43]

The fact that during this period she was abused neither within nor out of the relationship, must have pushed the idea that a relationship to a man is a way of circumventing many of the potential dangers a single young woman living in the townships of Cape Town is exposed to. This belief was to be painfully consolidated soon after. During one of the weekends of partying she followed a group of friends, this time without her boyfriend, to the neighboring township of Nyanga where in a tavern they got to know another person who invited them to his house for continuing the "night out". It was just after the men had left the house in order to purchase more drinks, leaving her behind alone, that "some gang pushed the door open. And I was gang-raped." She recounted how she was lying on the floor covered in blood with her face all swollen up when her friends eventually returned. [44]

Out of fear of being reprimanded for putting herself into such dangerous situations in the first place, however, she decided not to disclose to her family: "I went home and I got scolded for being away from home for the whole weekend and that was it." What emerged from here was a pattern of organizing her everyday life in which she constantly moved between the cultural milieu of township gangsterism and youth adventurism on the one hand, and her family on the other, without feeling safe in either. While moving within the terrains of peer sociality certainly provided her with the kind of excitement she was looking for at the time, it also created a strong sense of uncertainty against which the family could have been a haven of security and trust. However, it appeared to her that none of her youthful adventures would have been tolerable to her mother. On various occasions, Thembisa's mother actually admitted to me having been too harsh to her daughter, thereby possibly having contributed to the difficulties in familial relationships and—by implication—to her daughter's hardships. These, however, were only revealed to her much later. This harshness had left Thembisa with no other option than to perpetually strive for polishing her image as a *good daughter* in the familial context. The gap between this image and the sense of self she had meanwhile acquired within her peer circles virtually split her personal identity and progressively impeded the family from helping her move out of the violent environment of township youth culture. And yet it must be noted that adventurism was at once an instantiation of an emphatic idea of uncertainty, the fact of *freedom* as she repeatedly stressed. [45]

During the years to come, she went through a series of intimate relationships with men, all of which were marked by experiences of intra-relationship violence, sexual coercion and disappointment over her partners' unfaithfulness. Repeatedly, even when realizing the detrimental effects of these relationships for her life, she had trouble actually ending them. For months, sometimes years she continued being harassed by her former partners. While the experience of being abused by her partners now testified that for a young township woman "getting yourself a boyfriend" was far from being a satisfactory strategy in pursuing a secure life, she also understood that having a partner did not save her from abuse outside the relationship either. On one occasion, she was kidnapped in a street in the neighborhood and actually taken by car to another city where later she was brutally gang-raped again. Amidst these recurring experiences of debasement she tried leaving the pathways of alcohol, substance use and gangsterism, first by joining a Christian church community, then later by enrolling in a rehabilitation process in a therapeutic institution. Through continued social connections with former friends, both male and female, however, she always returned to the beaten tracks soon after. [46]

After having finished telling me the story of just another experience of abuse, she concluded in retrospect that "at this point being raped was not an issue anymore. It wasn't such a deal that I would say, 'Ok, this happened, I am crying. Think of it like I am raped again.' I just said, Ok, fine." But of course, it was anything but fine. Four years ago, she began having suicidal tendencies. She reported having tried to kill herself several times but always more or less half-heartedly. Eventually, in late 2005 she decided to seek help from a professional social worker to whom she disclosed her entire story. At the time of the interview, she still resided in a shelter for abused women, run by the public health system, to which to the social worker had referred her. [47]

In this moment, her autobiographical account had reached the present without her having mentioned the experience of her HIV-infection with a single word. It was only now that in continuing her narration she explicitly addressed her disease history:

"Oh, and then I got sick (...) I was dating this guy from work. And we hadn't slept together. From pick'n'pay. Before I worked for the organization I worked for pick'n'pay.<sup>8</sup> And I decided to date this guy at work. And we haven't slept together. And I am thinking, my life finally on track. Got back to school, have a boyfriend, good times with mummy. Life couldn't be happier. And I got sick." [48]

Subsequently, she had to stay in the hospital for three weeks where the physicians did various medical exams. From one of them it turned out that Thembisa was HIV-positive. Vividly she recalled how after having received the news from the HIV-counselor her hearing was impaired for a prolonged moment, how she would see the counselor's lips move without hearing a word of what she

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8 Pick'n'Pay is a big South African supermarket chain.

said. The subsequent descriptions of her experience within the following weeks uncover a quite typical reaction to the diagnosis of terminal disease:

"I am dead. I am dead. My life ended and I have no children, no husband, no nothing. And I am dead. And I am thinking this guy when I got sick he actually stuck with me. And I am thinking this is the one who actually did like me and I am going to lose him, I am losing him, I am losing him. Cause I know the moment I am telling, look I am HIV positive, he's gone. And I decided ok, I have to tell him as soon as I get better. So my mind was, I am thinking I can't go back to school, I can't work, I can't do anything because I will be dead in a few months, or few years probably." [49]

There is, first of all, a tremendous experience of loss, namely of everything in the future because the diagnosis has rendered virtually everything beyond the actual moment of survival radically uncertain and undermines her capacity to plan. Only now she began—step by step—revealing her entire story to her mother. In an attempt to eventually resume the role of the primary caretaker, her mother advised her to give up working and return to the family home. However, after recovering Thembisa soon realized that much of the care she was given somehow pushed her towards adopting aspects an *HIV-positive identity* she was not ready to accept. Instead of adopting HIV-infection as an important or even defining aspect of her sense of self, as HIV-positive people are actively encouraged by official public health concepts such as "living positHIVely" (see DILGER, 2005), she invested much of her energies in creating a sense of continuity in her life, even if this implied rejecting the care and affection she was offered by others:

"I don't like people that sympathize with me. I am a normal human being. And sometimes a lot I get on people's nerves. I like people who are honest, you know, don't judge me by my disease but by myself. So I don't tell a lot of people." [50]

Ambivalent and complex are also the ways in which her HIV-infection worked to reconfigure her relationship to men. First of all, she related that her current relationship did not survive the difficulties imposed by her disease. She reported how her boyfriend took great pains to be careful and supportive. But precisely by doing so he appeared to tie her to her disease in a way she was not prepared to accept. In the following, things became even more complicated: On the one hand, her HIV-infection seemed to provide her with a nearly perfect solution for her troubles with men. Whenever she faces unwelcome approaches she mentions being HIV-positive, "and they run away." On the other hand, however, when meeting a man she is interested in there is no way of circumventing disclosure. With frustration in her voice, she mentioned: "I am stopped by ten guys a day. It gets tiring saying, I am HIV-positive. And they are always like, I call you, I call you. And they never do." [51]

On yet another level, her difficulties with accepting the role of an "HIV-patient" may be unpacked through paying attention to her attitude towards anti-retroviral treatment. Unlike Palesa, for whom adhering to the wisdom of biomedicine, ARVs, and her concomitant engagement in public treatment activism were pivotal

for retrieving some level of biographical stability, Thembisa emphasized her determination to stay healthy without the support of biomedical products. In her view, ARVs—because of the need of life-long daily adherence to the treatment regime after initial enrollment—signified the opposite of living the kind of "normal life" that she eventually longed for. [52]

## **5. The Making and Unmaking of HIV-Positivity**

Because of its character as a terminal disease HIV/AIDS is likely to constitute a severe biographical crisis. It introduces a series of new challenges revolving around the opportunities of staying healthy, i.e. delaying acute AIDS as long as possible, and around the anxieties that the possibility of impending death evokes. Against this backdrop, the three biographical vignettes presented above have revealed how in the context of prior biographical experiences individuals find different pathways in dealing with such crisis, and how different trajectories are shaped in interaction with multiple social environments. The purpose of my reconstruction was not to deliver a discrete typology of the modalities through which HIV-positive women in South Africa deal with uncertainties ensuing from diagnosis. It was rather to highlight three fundamental aspects of dealing with HIV—processes of personal transformation, the mobilization of support, and the search for normality. While all of these aspects are to some degree intrinsic to the autobiographical accounts I gathered during my research, it seems that one of them was always most critically reflected. In this sense, however, as I have also tried to illuminate, any of the categories also constitutes an alternative perspective through which to look upon other narratives. [53]

Anxieties of dying are most strongly articulated in the experience of diagnosis. While in the accounts of my interviewees, emerging challenges have typically been linked to specific past experiences, the experience of diagnosis has almost uniformly been seen as utterly disruptive. Regardless of the meanings of life in their various cultural forms, the meaning of death emerged as a somehow autonomous category. As a signifier of death, the diagnosis invariably came as a moment in which all taken-for-granted assumptions just as the meaningfulness of our being-in-the-world momentarily dissolved. [54]

As people move out from this liminal state, new possibilities of life re-crystallize. What is striking here is the highly dynamic and flexible character of HIV-infection as a marker of self-identification. The flexibility allows for the various forms of the making and unmaking of HIV-positivity which the cases embody. For Maggie, self-identification with HIV was a transitory stage and she was more than willing to push her social work career away from AIDS projects. Her case can be construed as one of radical personal transformation, characterized by three consecutive choices of breaking with the past (terminating the cohabitation with her partner, abandoning her medical treatment regime, and the renouncing of intimate relationships to men). All of them are entangled with, ratified, legitimized, and dramatically enacted in the practice of conversion to Pentecostal Christianity. This is also evident in the vocabulary she deployed: The notions of acceptance, spiritual growth, of knowing oneself and salvation all belong to a language of

departure into a different future. At some point, breaking with the past also meant breaking from HIV/AIDS, as the ritualized act of throwing her medicine in the dustbin demonstrates. "Healing through conversion" had rendered the self-identification with AIDS redundant and invested uncertainty with positive meaning ("You never know what God is doing over night," as she confidently quipped).<sup>9</sup> In terms of DAVIES' conceptualization of temporal orientations, her case also shows how personal transformation may give rise to combinations and the sequencing of both, a philosophy of "living in the present" and a philosophy of "living in the future." [55]

For Palesa, on the contrary, the making of HIV-positivity was closely linked to the construction of a new life project, and at least during my field research period she did not show any signs of "getting tired" of AIDS activism and volunteering. After recovering from the shock of diagnosis and associations with death, AIDS had indeed become her life. Almost all of her activities revolve around AIDS activism, which takes shape as a dense network of support relationships in terms of both, giving and receiving. [56]

The diversity of forms of the making and unmaking of HIV-positivity as ways of self-identification particularly manifest themselves in relation to issues of therapy, medical treatment and healing. For Maggie, there was no point in taking ARVs when her process of transformation as "healing through conversion" implied that "HIV is not in my blood anymore." Thembisa rejected ARVs too, if for very different reasons. For her, ARVs were constant reminders of her HIV-infection and therefore appeared to thwart her idea of "living a normal life."<sup>10</sup> This way of constructing the meaning of treatment is literally inverted in Palesa's account: It is precisely the treatment that allows her to live a more or less normal life because ARVs are deemed the safest therapeutic option with regards to limiting uncertainties about her future health. For activists like Palesa, these drugs are almost sacred substances; for they give life. [57]

What is more, they are essentially understood as social substances in that the drugs and the activism surrounding them mediate social relations to others who are perceived as members of the same therapeutic community, and hence in a way, as people of the same kind. Indeed, I found that, particularly among patient-turned-activists, adherence to the "mantras" of ARV treatment created a profound perception of commonality not only in the sense of taking the same treatment but as a principle marker of common sense as such. Belonging to the therapeutic community of ARV adherents was seen as imparting the credentials of cultural

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9 It must be noted, however, that the viability of these concepts critically depends on a person's health status, and that experiences are therefore always open to re-interpretation.

10 Enrolling on an ARV treatment regime and successful therapy is tied to a number of conditions such as abstinence from alcohol and smoking for instance. Particularly for young people, this may require the changing of their whole network of friends if going out to *shabeens* (semi-legal township bars), taverns and parties without drinking is deemed unfeasible. Moreover, ARV treatment requires strict adherence in order to avoid the development of drug resistant viruses. Depending on the therapy cocktail, tablet need to be taken three to five times a day. In this sense but also because of the sometimes severe side-effects, ARV treatment often plays an important role in the organization of everyday life and remains a highly contested issue.

competence against which those who had doubts about biomedicine were branded as "denialists," if not as pretty much uneducated or backward. [58]

Activism as a way of living with HIV is mostly strongly contrasted to the search for normality that Thembisa's narrative revealed. In fact, the main goal in Thembisa's life is to live "as if nothing happened." Much to her frustration, achieving this goal is constantly undermined, for example by the need to disclose her status to potential partners. She rejects and even resents the sympathy she receives from others as a result of her disease, not least because it undermines her sense of authenticity. She wants to be judged by who she is, not by compassion for her suffering. Yet it is also the pain ensuing from the memories related to infection, the traumatic memories of abuse and violence that fuel these resentments. Moreover, her account shows how the experience of HIV-positivity may be largely subordinated to the search for, and orientation towards the re-insertion of socially standardized expectations into one's subjective experience, which the personal history of debasement has repeatedly impeded. In this context, ARV treatment is seen as just another reminder of what she does not want to be reminded of. [59]

Eventually, the analysis has highlighted how AIDS biographies and the diverging trajectories they entail are linked to the reproduction and re-shaping of social domains, such as civil society activism and politics and religion. Palesa's case can be seen as exemplary in terms of tracing biographical passages into South African AIDS activism that has captured sociological interest for more than ten years. At once we see how identity construction through activism creates barriers for participation, namely when it is seen as limiting the space within which life with AIDS is being imagined and projected.<sup>11</sup> As life with AIDS and the biographies through which it is narrated and written extend themselves in time, we will probably be confronted with much greater degrees of diversity of self-constructions beyond AIDS in the future, even if medical facts seem to limit them. [60]

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11 Similar contradictions could be observed during the 1980s in Western gay liberation movements when "coming out of the closet" was sometimes deemed to foreground sexual aspects of identity in exaggerated ways.

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## Author

Marian BURCHARDT works as a sociologist and is affiliated to the Department of Cultural Studies at the University of Leipzig. He has done field research in South Africa, the United States and India. His PhD thesis addresses the multiple relationships between religion and AIDS in South Africa from a trans-national perspective. His fields of inquiry include the sociology of modernity, sociology of religion, and very broadly the re-shaping of cultural diversity in the global age.

Contact:

Marian Burchardt

Department of Cultural Studies

University of Leipzig

Beethovenstr. 15

04107 Leipzig

Germany

Tel.: +49-30-26377182

E-mail: [marian.burchardt@gmx.de](mailto:marian.burchardt@gmx.de)

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