

“We are just afraid of what others may say about us”

Maintaining honour and respect in processes of disclosure in Bamako, Mali

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With the widespread availability of antiretroviral therapies in Mali since 2004, the physical aspects of HIV/AIDS have become less visible. Although the immediate danger of death no longer looms for patients, those on treatment must now live with a carefully guarded secret: their HIV-positive status. While most prefer to keep their status secret, a combination of medical advice, legal regulations and moral norms encourage disclosure. For most, decisions about to whom to disclose and how to confide their secret are a complex and risky matter in which notions of trust play a key role. Central to the anxiety around disclosure is a desire to preserve positive social recognition, conceptualized as the good name (tògò nyuman). The good name is of crucial importance for the maintenance of agency, and its loss is equivalent to isolation and exclusion, that is, to social death. This article explores the practical and reflective efforts taken by people living with HIV to balance the risks of disclosure with the desire to maintain honour and respect in their everyday lives. On the basis of two case studies taken from long-term ethnographic research, I demonstrate the dynamic aspects involved in dealing with disclosure, and illustrate various ways of communicating about the disease in different settings.

[HIV/AIDS, antiretroviral therapy (ARV), disclosure, honour, trust, Mali]

*Good name in man and woman, dear my lord,
Is the immediate jewel of their souls:
Who steals my purse steals trash; 'tis something, nothing;
'Twas mine, 'tis his, and has been slave to thousands;
But he that filches from me my good name
Robs me of that which not enriches him
And makes me poor indeed.*

(Iago in 'Othello' by Shakespeare)

Introduction

In the course of every fieldwork experience there is someone with whom you establish more closeness than with others, often without really being able to name the reasons for this familiarity – “*où le courant passe bien*”, as people in Mali will say. For me this person was Mariam.¹ When we first meet in 2004, she is 28 years old and working as a nurse in the laboratory of the local centre specializing in HIV/AIDS. When I pass by her workplace on one of the first days of my field stay, Mariam signals me to come in. Even though no one else is present, she talks to me in a whisper and manoeuvres me behind the large refrigerator where the supplies for the HIV tests are kept. She says she heard the physician introduce me to the staff the day before, and she needs to talk to me about an urgent matter – no one else is supposed to ever know about this conversation. A bit irritated at the oddly secretive atmosphere and also concerned about becoming implicated in tricky internal affairs, I am hesitant at first, but then promise to get in touch with her again.

Three days later, just after dusk, we meet at my place. As agreed, Mariam ‘beeps’ me with her mobile phone right before she arrives, so I can open the garage and allow her to hid her moped from passers-by. Inside, and out of sight of the guard, she removes her cap and oversized sunglasses. Although it is extremely hot and stuffy, she does not want to sit on the porch – instead, she suggests we retreat into a room and even close the windows to ensure she is not overheard. Although I am quite irritated by what seems to be slightly overstated secretiveness, I put two blankets woven from colourful plastic strips on the floor and serve a jug of tea. Once seated she tells me that she is about to disclose a secret that is only known to herself and two physicians: she is seropositive. She received her diagnosis half a year ago, but had suspected it for some time. She also tells me the reason she works at the health centre is that it gave her the chance to get free antiretroviral treatment at a time when it was very expensive. But nobody, absolutely nobody should ever learn about her disease. This I must promise her there and then.

Our whole relationship was marked by this secret. While it created complicity between us, it also lent a strangely conspirational character to our future encounters. In the presence of others we acted as if we were only casually acquainted. Mariam was convinced that any closeness with me was likely to raise suspicion because I was conducting HIV research. Since I have known her, no one else has learned of her infection – neither her mother nor the man she would meet and marry a few months later. She says that she keeps her HIV status a secret because it is a *bombe sociale* – once exploded, it would have tremendous destructive force. Although the biological aspects of the disease can be controlled with antiretroviral therapy, the gossip of those around her might jeopardize her social existence. Her good name is at stake, something Mariam will undertake everything to protect it.

Prior to treatment becoming available, the disease eventually found a way to make itself obvious without words, making personal and explicit disclosure often unnecessary. If people decided to inform someone about their infection, their driving motivation was often hope to receive financial help to pay for urgently needed medications

(see e.g., Mogensen 2010: 69; Whyte et al. 2010: 15). With treatment now available, people are able to hide their status, which means that being open has come to be a more voluntary decision. Many now live with the fear of not being able to keep the secret, and the consequent loss of their social recognition. To confide in someone is fraught with risk – illustrated by the saying: “if one person knows, everyone knows”; the more people who know, the greater the risk of being betrayed. Were it not for the practical or moral reasons that made it necessary to share such information, most people I interviewed would have preferred to keep their secret. Although people commonly agreed that HIV was too heavy of a burden for a person to bear alone, decisions about disclosure are a very complex matter. It is a decision that takes time, and is often accompanied by persistent uncertainty, questioning and doubts. In this context notions of trust seem to take a prominent role and assume special meanings.

At the very focus of all fears and dangers is a phenomenon pertaining to social recognition. Being of decisive importance in everyday interactions, it is considered to be a matter of course under ‘normal’ conditions, and thus rarely spoken about explicitly: the good name (*tògò nyuman*). As expressed by Iago in Shakespeare’s play ‘Othello’ the good name is an immaterial possession the loss of which can entail consequences much graver than financial damage. It is not only a symbol of an individual’s inner wealth, but also the basis of social wealth. Associated with issues of belonging, social identity and – most importantly – related to the agency needed for everyday life and survival, the loss of one’s good name is equivalent to isolation and exclusion, that is, to social death. Although this phenomenon seems to be, as Iago’s speech suggests, a universal form of social recognition, even with a historical depth, it nevertheless has particular features and meanings that are shaped by local conditions. Narratives of people living with HIV in Bamako stress the many risks to which their name is exposed, but they also describe their practical and reflective endeavours to protect, redefine or regain their name.

Ever since the early years of the epidemic, issues of disclosure have been of great concern for patients as well as for those working in the field of HIV/AIDS. Scholars arguing from a public health perspective have emphasized the positive effects of disclosure on HIV prevention and compliance (i.e., Do et al. 2010; King et al. 2008; Serovich et al. 2008; Waddell & Messer 2006). Generally speaking, after the introduction of antiretroviral therapy (ARVs) more importance became attached to openness. This was due to worries that with the possibility to hide the disease, the epidemic might spread at a faster rate. When the era of life-saving treatments began, access to treatment became closely linked to being open in several African countries. Nguyen et al. (2007) show that public confessions were more or less a precondition for obtaining the drugs in Burkina Faso. The situation was quite similar in Mali. In some countries, in order to be eligible for treatment people living with HIV must be accompanied by a treatment assistant (a so-called ‘buddy’), someone who is informed about their diagnosis and helps them comply with the medication regime (see Mattes 2012; Schneider et al. 2007). Recent studies from Africa pay special attention to the impact of ARVs on disclosure. Mainly based on cross-sectional design and regarding disclosure as a discrete act, they identify various risk factors as well as patterns and determinants

related to disclosure (Gilbert & Walker 2010; Lubiere et al. 2009; Miller & Rubin 2007; Mucheto et al. 2009; Salami et al. 2011; Titilope et al. 2011).

In this essay I take a slightly different perspective. Even though some scholars predict that these now widely available therapies will spawn a process of normalization, over the course of which the stigma will disappear (Sow & Desclaux 2002: 170), and others claim that the disease can be treated like any other chronic condition (Gilbert & Walker 2009: 1126), valuable insights may be gained from longer-term research on how people living with HIV handle information around their diagnosis, and how they balance different forms of disclosure with their desire to sustain honour and respect in their everyday lives. The two case studies presented here clearly illustrate the process-related aspects of disclosure. At the same time, they highlight the fact that openness is not simply a one-time-action but rather a meandering flow between manifold modes of hiding and exposing, where notions of trust play an important role.² In order to gain a differentiated understanding of the social complexities involved in these processes it is illuminating not to confine oneself only to an analysis of the risks. Rather my main focus here is on how people living with HIV navigate these changed landscapes of risk, and the innovative and future-oriented options they open up for themselves during these processes. The case studies and findings presented in this contribution are based on data collected during fieldwork conducted over the course of four years, which enabled me to closely witness the dynamics of people's various initiatives over time.

Methods

In the course of six fieldwork periods (from the end of 2003 until early 2008), which amounted to a total of 15 months, I talked with 27 people about their illness experiences. All the participants in the study were qualified for access to ARVs. In this context, I explored the risks they confronted and the constraints that guided their actions, with a particular focus on the strategies and tactics they pursued to avoid what they feared most: loss of social recognition. In total, I conducted 81 in-depth interviews with 17 women (aged between 20 and 52) and 10 men (aged between 23 and 56), who came from various economic and educational backgrounds. Contact was mainly established at CESAC (Centre d'Ecoute, de Soins, d'Animation et de Conseil pour les personnes vivant avec le VIH/SIDA), a clinic specializing in HIV/AIDS-related treatments and care, and the location where most of the interviews took place. The centre is located in the heart of the city between the railway station, post office and market, in the thick of the hustle and bustle of Bamako. Up to 150 patients visit the clinic each weekday, arriving early in the morning and sitting for long hours on metal benches, waiting their turn. After the consultation, they usually stop by the pharmacy, which is situated among centre's buildings, to have their prescriptions filled.

In the first weeks of fieldwork I stayed at the pharmacist's side, benefitting from his competent knowledge about the family situation of nearly every patient. For reasons of confidentiality, patients enter the pharmacy only one at a time, which gave me the opportunity to engage in casual conversations with them as well as to share some

information about my research project. Although this was a perfect place to casually initiate contact with potential participants, the arrangement had a downside: I was identified as belonging to the staff of the centre. This association made it sometimes difficult to create an open atmosphere during subsequent interviews, particularly because participants felt obliged to present themselves first of all as good and compliant patients (Goffman 1984). These tendencies could only be attenuated through repeated encounters, which eventually led to a form of dialogue that was much more open than usual and that allowed my interlocutors to talk spontaneously about matters normally charged with guilt and shame.

The research process as a whole, which was guided by the principles of grounded theory (Strauss & Corbin 2008), was divided into two different stages. The first stage involved an explorative phase, including a period of recruiting participants. I did not only look for participants with specific experiences relevant to my research topic, but also for a broad sample in terms of age, education and socio-economic background (*theoretical sampling*). Before conducting the first interview, I informed every participant about the voluntary nature of participation and handed her or him an informed consent form to sign, which was prepared in consultation with the directors of CESAC. During these first encounters, I used guided interviews in order to get a deeper understanding of the interviewees' personal context, their illness trajectories and, most importantly, their socially problematic situations. In subsequent conversations, I focused more on learning about the different ways of coping with the manifold risks of losing social recognition. Due to our already well-established relationships, the interviews gradually took on a more open form. As a result, the methodological approach changed from semi-structured interviews to conversations with a narrative character.

The interviews themselves were conducted either in an empty room at CESAC or, if preferred by the participants, at my home. They were all recorded on tape, either in French or in Bamanakan – which is the lingua franca in Mali, alongside French. Although my Bamanakan was sufficient for everyday use, I often relied on two trained co-workers to assist me with translating; they also provided invaluable support in discussing preliminary analyses and diverse interpretations of particular passages.

Subjective experiences and the individual struggle to preserve honour and respect in the face of a stigmatized infection are shaped considerably by societal conditions such as international funding, political will, the activities of NGOs and, not least, discourses about HIV/AIDS. I therefore held 12 focus group discussions with younger and older citizens of Bamako, which yielded information about collectively shared attitudes (Flick 2005: 171). In addition, I talked to relatives of those infected, provided that the situation allowed this.

Since the collection of data extended over a period of several years, I had the opportunity to keep track of long-term processes. This provided me with deeper insights into the often complex situations that accompany disclosure, while at the same time giving me the opportunity to witness important changes in the subjectively perceived "landscapes of risk" (Davidson 1991, quoted in Green & Sobo 2009: 39) and the manner in which their contours shifted due to ARVs. I kept in constant touch with

both of the two women introduced in the following case studies, over more than two years and almost four years, respectively. Their actions show that disclosure has to be understood as a social process where actors simultaneously navigate different forms of openness.

Living with a secret – An altered landscape of risk

In Mali, the political will to wage the so-called ‘fight against AIDS’ became manifest quite early in spite of the comparatively low prevalence of HIV/AIDS (between 1.7% and 3%, depending on the sources consulted). However, efforts mainly focused on the medical aspects of the disease. As early as 1987 the *Programme National de Lutte contre le SIDA* was implemented. During the 1990s this was followed by treatments specifically tailored to the disease; however, these treatment options were only available in the capital of Bamako. A fundamentally new era began in 2004, when a state-run programme began administering free ARV therapies to those who met certain medical criteria. Since 2004, additional distribution and treatment centres have been established in various places throughout the country. Despite widespread treatment availability, the social perceptions of both the disease and those infected have hardly changed. Since the onset of the epidemic AIDS has been closely linked to prostitution and adultery in Mali, and remains viewed principally as a *maladie honteuse*, a ‘disease fraught with disgrace’ (see, i.e., Attaher 2005: 33; Le Palec & Pagezy 2003: 95f; Maiga et al. 2007: 6f). Such views make it particularly difficult for HIV-positive individuals to disclose their status.

As everywhere in the world, the issue of disclosure is also in Mali regimented from many sides, as disclosure is constructed as a medical, moral and legal obligation. Epidemiological arguments, concerned with containing the spread of the disease, advocate a more open way of dealing with the infection. Attending physicians encourage patients to confide their diagnosis to someone who will help them adhere to the strict dosing regimen. Legal regulations stipulate that HIV-positive individuals must inform their sexual partners within six weeks (Présidence de la République 2006: article 27). If individuals fail to do so, health care professionals are called upon to report them to the authorities; however, most physicians I talked to viewed this instruction as running counter to their obligation to maintain confidentiality. Besides meeting medical, epidemiological and legal requirements, HIV-positive individuals need to realize their own goals and projects and live up to their own moral standards; most importantly, they need to consider the social consequences of their actions. Any decision to confide in someone is thus influenced by conflicting interests. Many patients are overwhelmed by this burden, becoming immobilized and endlessly postponing disclosure until later.

All the patients in my sample belong to the first generation of people treated with ARVs in Mali. Prior to beginning the therapy, most of them suffered prolonged phases of sickness, with symptoms that are typical of AIDS. During those times, suspicions about the nature of their disease were uttered in their social circles. Nowadays, as they apparently have recovered, these voices have fallen silent, but the suspicions, how-

ever, are not forgotten – any information pointing in that direction is thus considered quite plausible rather than being dismissed as malicious defamation. In this sense, the patients of the first generation are living with a highly precarious ‘secret’, as most of my interlocutors name their not-revealed diagnosis, preferring this social expression instead of a medical term like ‘seropositivity’. Having been ill in the past, a special situation that characterises this first generation, they are particularly discreditable and must live with a high measure of uncertainty: any hint or act of betrayal may shift their position from being discreditable to being discredited (see Goffman 1963: 12).

As can be easily comprehended, secrets always have “relational meaning” (Spitznagel 1998: 29), particularly if they concern something as grave as HIV. They change, or, more precisely, burden relationships irrespective of whether they are revealed or concealed. To share a secret always means to bestow power on the person one confides in and thus to be at his or her mercy once shared, the information can no longer be controlled. People do not know how the person privy to their secret will act in the event of conflict; they are dependent on his or her loyalty; and they must always reckon with the possibility of blackmail or betrayal. It comes as no surprise that those affected often shun the risk involved in divulging their secret. On the other hand, these concerns bring people to test the trustworthiness of their significant others, since many HIV-positive individuals no longer perceive the disease as the main risk, but rather the rumours, the words of others that could result in social death:

We are not afraid of the disease but of what others may say behind our back. It’s the words of other people that can spoil my name. The disease is here. But the disease doesn’t speak. The disease itself says nothing. (f, aged 29, 13.2.2005)

In their contribution, which frames secrecy around HIV as an embodied practice, Hardon and Posel (2012) elaborate on how the will to conceal is often subverted by bodies that unwittingly reveal. In my research, however, people seem to be much less afraid of what their bodies might reveal than of what might be uttered by the mouths of others – perhaps a logical response for the first generation to have a strong faith in the power of medicine. However, in an environment perceived as very talkative and hungry for sensation – “here, gossiping is like breathing” – the risk of falling victim to rumours due to an ill-considered disclosure is thought to be particularly high. In addition, the proverbial anonymity of large cities is only found to a limited degree in Bamako. In spite of the fact that the city now has almost two million inhabitants and is expected to become the fastest growing city of Africa (City Mayors 2006), the residents themselves describe Bamako as rural: *bèè bèè u don* – everyone knows everyone else, and all inhabitants are, in one way or another, linked by social bonds. This means that the environment is conducive to a rapid circulation of secrets, and the more these collide with the dominant norms, the more sensational they are. People living with HIV thus anticipate that news about their secret, once divulged, will spread like wildfire. In addition, they believe that the stigma of HIV will stick to their descendants for generations – even after their own death, it will haunt their children and grandchildren, and besmirch the reputation of the whole family. The impact of betrayed trust

seems almost infinite in its temporal, spatial and social dimensions; consequently, any disclosure is viewed as fraught with risk. Imaginations about “what would happen if others knew” are a recurrent and major theme in the narratives of HIV-positive people, revealing the big, burdensome fears and uncertainties that go along with this secret. In this context, it does not matter whether these scenarios actually come to pass.³ It is beyond doubt that such fantasies have a large impact on people’s thoughts, acts and feelings, and thus structure their everyday life in a decisive way.

The good name (*tògò nyuman*)

For HIV-positive people, fear of losing their good name is at the very focus of their risk perception. Still, it is difficult to articulate what exactly is meant by a person’s name. A statement made by an elderly man in the course of a focus group discussion provides some initial clues:

Your name is you – it’s your social value. Here we say: *Mògò ye e tògò dè bolo* (literally: A human being is in the hands of his/her name, he/she is his or her name). Your good name is an extremely important thing. Without a name you can’t do anything in your life. (m, aged 47, 31.1.2007)

A person’s name thus gives information about his social value, how he is perceived by others, and whether he can be trusted. An individual’s value is determined by others, for it is their words that constitute a person’s name: “Your name comes from the mouths of others”. While the foundation of one’s name is based upon their character traits, way of living, and relationships, how others judge one’s inner qualities and actions is far more decisive. Rather than being an authoritative and stable entity, one’s name depends on the evaluation of others, and is thus susceptible to all possible forms of positive and negative manipulation. This concept of the name ranks among those African concepts of honour that have become clouded over the course of history, losing much of their original character. Nevertheless, the concepts could never be completely tamed by either Islamization or colonization, and thus still exist today, though in fragmentary form (Iliffe 2005: 31ff).

This definition from outside, from the judgements of others, is also reflected in the etymology of the term *tògò*, which is an abbreviation of *to n’ko* (‘that which stays behind me’), which refers to the manner people talk about someone in his absence and, in the broadest sense, after his death. Indeed, a proverb says that the name is the only thing death can’t destroy (Cissé 1971: 157). As a form of everyday recognition, the name meets the defining criteria of “horizontal honour”: the entitlement to be respected among equals (Stewart 1994: 54). A good name is thus maintained not by extraordinary actions but by everyday conformity. As is the case with all phenomena related to honour, a damaged name affects all spheres of action and all social roles.

A good name is formed by successfully meeting an ensemble of criteria articulated in the Islamic concept of *adamadenya* (literally: the matter of Adam’s children). Hav-

ing a good name refers to an individual's sociability – the ability to maintain harmonious relationships with others and to lead a life in accordance with religious rules. This includes moral integrity as well as financial independence. Only those who fulfill these normative expectations can reap social benefits and social trust. In Bourdieu's (1985: 22f) sense, the 'symbolic capital' of honour serves as a passport that grants access to other types of capital – particularly social and economical – and thus social participation. This meaning is conveyed by what one young man said about the consequences of a damaged name:

Relationships with people from outside can deteriorate, your friends can completely break away from you. (...) And this will have an effect on your financial means. It's difficult for people to accept you. If your name is spoilt, this will kill you socially and demoralize you. The social has great importance, in every relation. The social is something that outranks everything. If you are socially not accepted, you can do nothing. A man can't do something on his own, he has to be accepted, appreciated in society in order to bring off his projects. (m, aged 29, 20.11.2006)

A name that is damaged – a spoilt name (*tògò tyien*) in Bamanakan – has grave consequences and is viewed as the equivalent of social death. However, the concept of name in Mali differs from Mediterranean concepts of honour; the latter follow a codified system, in which damage always entails loss (on this, see Peristiany 1982; Pitt-Rivers 1966; Stewart 1994). In Mali, there is a continuum between a good name and a damaged name; clear acts of exclusion are preceded by various stages of accusation, including suspicions, allusions and rhetorical traps. During these stages, people surrounding the questionable individual try to find out whether the circulating rumours are true. These 'name ordeals' are perceived as acts of obtrusive curiosity by those affected, and as very disquieting. Their concern to conceal their infection is now confronted with an intent to expose it, and to provoke disclosure:

They ask me if I know somebody personally with AIDS. And once even a neighbour said to me: "Have you seen someone with HIV? Can you show me someone who has AIDS?" They want to provoke me so that I have to say it myself. They just want to hear it from my mouth that I am seropositive. (f, aged 37, 17.2.2008)

During this stage, which is characterized by a mode of communication called *ka kòrò-matigè* (to allude to something, to criticize) and indicates that someone's name is damaged, words are still vague and not directed at anyone in particular, though it can be assumed that everyone knows who is being talked about. If the suspicion is substantiated, however, the remarks become much more explicit:

If people know about your disease, they say things in front of others who are normally respecting you and this makes you feel ashamed. When you hear these words, this brings dishonour and gives you a lot to reflect on. (f, aged 20, 29.7.2004)

At this point, people's feelings become badly hurt because they are exposed and ridiculed – or, to put it differently, because they are forced to be present at the negotiation of their own names. Simmel (1992: 396) refers to honour as an “ideal sphere” that surrounds every human being, which cannot be penetrated without degrading the personal value of the individual. However, this social ‘sheltered space’ disappears once someone's name is damaged; as a result, people are vulnerable to abuse by others. Another common experience related to having a damaged name, and one no less threatening to those affected, is expressed by the term *ka denkèrè fè* (to put [someone] aside):

When they are doing *ka denkèrè fè* to you, this means that you will stay alone. Nobody talks to you and only bad ideas are in your head. People say nothing – even things that would be of some importance to you, they will withhold. You are a person without any importance, it is as if you do not exist. (m, aged 41, 22.1. 2007)

Damage to a name never affects the individual alone. Disgrace rubs off on those who are in contact with the person whose name is tarnished:

When your name is spoilt, you are ruined. Not just your life is ruined, but that of your family, and that of your children. And all your acquaintances are embarrassed by the fact that your name is spoilt. (m, aged 60, 31.1.2007)

On the other hand and particularly in the time of ARVs, family members have a special position of power within the context of name negotiating – a constellation I will further discuss in the case studies that follow.

Disclosure and trust: Gaining a confidant

When we first meet, Mariam is living with her mother and three younger brothers in a rented accommodation in a compound. She has a room of her own and thus enough privacy to take her medication without being disturbed. In this respect, she is in a well-organized and sheltered situation as far as secrecy is concerned. On the other hand, however, she is 28 years old, and it is about time for her to leave youth behind and get married. After all, it is only as a married woman that she will gain the recognition granted a grown-up and full-fledged member by society.

When we see each other again half a year later, Mariam has obeyed social convention and is now married to a government employee twenty years older than she is. The decision has been made in a rush – not even a month had elapsed between the day they met and the wedding. Though Mariam thinks that honesty is one of the pillars of a good marriage, she does not know how to tell her fiancé, who has already been divorced six times, about her diagnosis without bringing his good intentions to naught. She suggests that they undergo an AIDS test together.⁴ However, her fiancé is not interested in doing so: he says he does not believe in AIDS, and that he trusts her. This makes Mariam realize that she cannot further push the issue; if she does, he will

grow suspicious, and the wedding will be at risk. Thus, she postpones her disclosure until later.

But alas, married life is much less harmonious than she had hoped. The initial tenderness is gone, and her husband turns out to be quite authoritarian, which makes it all the more stressful for her to hide her medication and to ingest it hastily and secretly. She seriously asks herself how long it will take until her first mistake:

Often I just sit around and think about my situation. I can see I am really overwhelmed. And I ask myself what can I do to return to the past and tell my husband: "I shouldn't marry you because I am seropositive" I should tell him this. (...) But now I can't say that I already was seropositive when he found me. I will keep my silence about this, I can never reveal this to him! He will just go out and tell everybody that I only got married to contaminate him. (13.2.2005)

If Mariam confided in her husband, the threat posed by the worst-case scenario would be ever present – even if he kept the information to himself – and her position within the marriage would be weakened. On the other hand, she is increasingly haunted by disquieting fantasies about the consequences not only for her marriage, but also for her name should her secret be disclosed. Thus, she feels that she badly needs at least one confidant who will get her the appropriate medication in case she falls ill.

"To gain a confidant" – this expression was often used by other informants in conversations, too. To find a confidant is, so to speak, the precondition for disclosure. On the one hand, this bespeaks the need for support from someone who is not only unconditionally reliable but also able to give advice. On the other, the expression points to the proactive possibility of building trust, to establish a relationship with someone in order to make trust more reliable and risk more bearable. For Mariam, this person must be someone on whose discretion she can absolutely rely. She points out: "In matters of secrets, first of all there has to be trust. Someone who says trust, says confidence and says secret." Theoretically, her mother would make a perfect confidant because betraying Mariam's secret would hurt her mother as much as it would hurt Mariam; yet, this option is out of the question for Mariam. Her mother suffers from high blood pressure, and it would thus be hard for her to cope with the news. In addition, this step is much too fraught with shame for Mariam, because she fears that her mother will think she is promiscuous. A second potential confidant would be one of Mariam's close friends. Mariam begins to 'study' this friend, and tries to read from her reactions whether she is really compassionate or mainly pursues her own interests. One particular incident arouses Mariam's suspicion, eventually dissuading her from divulging her secret: her friend is crazy about one of Mariam's dresses but stubbornly refuses to accept it as a gift. Interpreting this attitude as a sign of envy, Mariam believes her friend does not want Mariam to be able to position herself as a giver, and thus as superior. Mariam thereupon decides not to confide in her, because:

I studied her, but I can't tell her this [the diagnosis, N.S.]. Why not? I noticed she is jealous of me. And she became ungrateful. Someone who is jealous does not want your

happiness, she just wants to defame me, say things which bring me down and that's why I haven't been open to her. Because with everything, you have to reflect before you act. (26.3.2007)

She says that as a third possibility, her younger brother Ali *automatically* came to her mind. Ever since he was born, the siblings have been particularly close; Mariam has constantly encouraged and fostered this closeness by financial contributions and gifts. Among other things, she is funding his third attempt to graduate from high school. While Ali appreciates her generosity, he is also aware of the fact that her contributions carry an obligation. When she finally takes the courage and confides to him, his reaction is exactly as she has hoped – he does not accuse her of anything but sees her illness as a matter of fate, and he promises to never divulge the secret to anyone. This trust is additionally strengthened by the special relationship between brother and sister:

When I share 'same mother-same father' with someone I can trust this person since the tie descends from one bed. And that's why the person can keep a secret. ... Don't trust somebody when you are not bonded by blood and the maternal breast. It's the blood and milk you have drunk which unify you for better or worse. You can never betray the milk you have drunk. But if you only have the same father, you can't have trust. (18.11.2006)

In the preceding quote, Mariam points to a social institution – *badenya* – in which trust is already predefined as an ideal; this term refers to children born to the same mother in the context of polygamy.⁵ *Badenya* stands in contrast to *fadenya*, the relationship between children of the same father, which tend to be characterized by competition and conflict. *Badenya* however is characterized by a high measure of trust and solidarity, and explicitly the keeping of secrets (see Roth 2004: 116f; Vuarin 2000: 77). The relational framework thus has decisive influence on the emotional qualities that take effect in it. Unlike the relationship between husband and wife, in which trust as a defining element is not predetermined by the relationship structure, a younger brother by the same mother offers safety. Mariam explains this ideal with reference to shared blood and milk, emphasizing the low risk of betrayal inherent in this relationship. However, the institution of *badenya* does not guarantee safety; solidarity needs to be actively produced, that is, continually cultivated and nourished, in order to remain stable. In this respect, Mariam's trust in her brother is not only safeguarded by intimacy and a social institution, but also by continuous material investment into – to quote Bourdieu – 'social capital', which in turn has a positive impact on her symbolic capital: her name.

Basically, each act of trust points to a still undetermined future, and is characterized by a "problematic attitude towards time" (Luhmann 2000: 9). By showing trust, an individual anticipates and acts with confidence toward the future. On the other hand, trust needs time in order to develop: "Trust doesn't come in a single blow, it comes with time" (m, aged 41). Mariam, however, did not feel that she had much time – her wedding had been arranged in such a hurry that she did not have time to build trust and to inform her fiancé. We need to keep in mind that women are under tremen-

dous social pressure to get married and become recognized in society; hence, many of them insist on a quick wedding, as they are driven by fear of losing their suitor to some other, better-off, female competitor (see Lardoux 2004). The social recognition gained through marriage is in this way an obstacle to the type of openness called for in medical, epidemiological and legal contexts – an openness that may itself jeopardize social recognition.

The trust between Mariam and her brother Ali, on the other hand, had ample time to develop over the course of 22 years, and is embedded in their joint history. Their temporal horizon of trust not only extends into the future, but also – and even more decisively – into the past. Trust, according to Endress, is grounded in constellations of intimacy; it is a mode of negotiating between past and future for purposes of orientation in the present (Endress 2001: 174f). Mariam's use of *badenya* automatically invokes this intimacy, reflecting a high degree of casual and unquestioning confidence.

This understanding of trust, as used in the preceding paragraphs, is oriented towards safety rather than risk. In the context of HIV disclosure in Bamako it seems appropriate to speak of 'embedded trust' – trust that is embedded not only in intimacy, characterized by a feeling of equality and emotional closeness, but also in the readiness to give material support.

The next time I meet Mariam, she has separated from her husband. She seems very much relieved. Since it is her husband who is viewed as the guilty party in the breakup – due to his six previous divorces – she says that her name has not suffered any harm. At any rate, one positive effect of her brief marriage intermezzo is that she is now regarded as 'disappointed by life', which means that she is not expected to remarry within the next five years or so; at least this is her guess. She plans to use this newfound time to further pursue her professional education.

Disclosure and respect: Presenting gifts to the family

There was a time when AIDS was not yet perceived as a real threat but rather as something only present in the media. Amy still vividly remembers how people used to tease each other about having the disease: "Eh! You have AIDS, hey! No, it's you who has AIDS!" Even at that time, however, she had forebodings that sooner or later the virus would be discovered in her blood, too. Today, she can hardly imagine having such a naïve and careless manner of dealing with the disease. In 2004, when we talk to each other for the first time in the consultation room of CESAC, Amy is receiving the new ARV therapies but does not yet trust their efficacy. After all, she is still haunted by recent experiences and thoughts of dying lonely and miserably.

Amy tells me that after her marriage ended she returned to the place where she had grown up; she lives there with her 15-year old daughter, her mother, and her two sisters, in the cramped conditions of a compound inhabited by several families. She has fallen ill over and over again; deciding to undergo a HIV test, she informs her mother of this plan. Her mother wants nothing to do with it, and never asks about the outcome of the test. Amy interprets her mother's behaviour as a request to keep silent about the

diagnosis, and she complies with that request. But despite the many treatments there is no sign of recovery – to the contrary, symptoms typical of AIDS become more and more evident. Her friends begin to shun and withdraw from her, and insulting remarks are made in Amy’s presence. Soon, even her sisters begin to avoid her and openly hurl abuse at her, calling her a *sidéenne* (a person with AIDS). When even her daughter refuses to bring a cup of water to her bedside, Amy is so deeply hurt that she no longer wants to have her around and sends her to live with her father.

Given these experiences, Amy has little hope that things will improve – people do not think much of her. Amy desperately yearns for a new beginning, somehow. But how can this be accomplished? After all, she thinks, everyone knows that she is sick with AIDS. She says that marriage would definitely be the best solution, all the more so because it would ease her family’s financial burden. But finding a suitor after all her illnesses is absolutely unrealistic, she thinks.

Half a year later, I encounter a completely changed Amy – stylishly dressed, full of zest, and involved in new projects. She tells me that her soul has recovered (*n’ka kènè n’ni na*) and that her principal focus is now on earning money: “I want to work to look after my family.” Amy is using her disease as a source of income: she has become a member of a self-help group for HIV-positive people, and has a side job as a receptionist at CESAC. Through these connections, she is always one of the first to learn about activities and financial opportunities, and she gets a regular, modest fee for participating in awareness-raising events (*témoignages*), where she talks about her own infection. However, she sees to it that these *témoignages* are scheduled only in places slightly outside the city – where no one knows her. The income thus earned she shares with her family:

The best for me is, first of all, to ensure there is food for my family. This is the most urgent need. (...) Today, I love to offer gifts to my family. When I am making *témoignages* I keep the money I get. (...) I like to buy a kilogram of fish and rice to please my whole family. (f, aged 38, 26.1. 2005)

A very lucrative opportunity offers itself on the occasion of World AIDS Day. Amy participates in the Miss AIDS contest, which is broadcast live by Malian television. Of course, this public appearance piques curiosity among people in her local community, given the fact that she outs herself as HIV-positive and thus adds fuel to old suspicions. However, Amy cleverly takes refuge in her role as a CESAC staff member, saying that her confessions have been purely professional. This makes her fit in with the general image of the AIDS sector, widely viewed as a lucrative market due to the enormous donations it receives and the daily media coverage thereof. The Malian audience tends to view *témoignages* as similar to commercials – staged clips with certain show qualities that have nothing to do with the prevalent image of emaciated people, sick with AIDS. Against this backdrop, people find it plausible that Amy is shrewdly using her talent as an actress in return for a good fee.

This risky approach to information management – combining medical confession, public denial and private silence – is a challenge in many respects, and only successful

under specific circumstances. Family members play a crucial role. Amy's family has watched the broadcast as well, yet never lets slip a word about it – not a comment, not a question. While Amy is quite sure that everyone knows, but respect forbids people from explicitly addressing the issue. In the family circle, the disease has the status of a secret that is shared but never spoken about, and screened from the outside world (see Keppler & Luckmann 1997: 208). This results in the establishment of a special form of family bonding that feeds on Amy's readiness to share her earnings from the AIDS sector and thus to assume a new level of responsibility, one which resembles that of the head of a family. Several publications in the context of HIV/AIDS deal with the limits of family solidarity and show how rarely seropositive persons can count on the support of their loved ones (see Attané & Ouedraogo 2008). In this case, however, it is the infected person herself who, through activities in the AIDS field and particularly through public confessions, makes a substantial contribution to the livelihood of her family.

Besides such financial contributions and information management efforts, specific forms of self-representation – the “work on an image intended for the eyes of others,” as Goffman (1967) puts it – constitute an indispensable component of Amy's attempts to achieve social recognition. In this context, the most important feature is her choice of clothing. In the course of my daily presence at CESAC, I am struck by the attention Amy pays to her outward appearance and by the care with which she selects her clothing. A freshly ironed ensemble, a well-draped scarf and, most importantly, the document folder she always carries with her – all these are supposed to convey the impression that she frequents CESAC as an employee and not as a patient. These outward signals add to the image of professional authority that is part of her new identity, which is also reflected by the fact that people will sometimes address Amy as ‘docteur’.

Some eight months later Amy's ambitions seem to have come true. Not without pride, she reports: “I have health, I have money, I have people who love me – today I am admired by all.” She says that she can now reap the fruits of her labour. Not only has her position in her family stabilized, but her relatives also praise her good deeds in the presence of others, with the result that people in her social environment view her in a different light and respect towards her has been restored. Social recognition may be a public good, but both its foundation and the seed for its disintegration rest within the family. While HIV/AIDS scholarship usually portrays family members as victims because they are affected by the same stigma as the sick person, from the view of infected persons, family members occupy a position of considerable power.⁶ Their testimonies are considered reliable, first-hand information; now that the disease has largely been rendered invisible, the statements of family members have come to replace the signs formerly associated with AIDS. They have the power to confirm or invalidate suspicions that circulate, as well as to start new rumours.

To know something without talking, to guess without asking – this ambiguous way of information management is an alternative to both personal disclosure and conscious concealment. One of my informants, a man whose family also suspects his diagnosis without being informed about it *expressis verbis*, told me it is not worth the trouble of openly addressing something that only brings shame and jeopardizes

the respect between the family members. Words merely trivialize his disease, he said, because they make it appear banal and unexceptional (m, aged 42, 4.1.2008). The appropriation of intermediate spaces, located beyond unambiguous statements, gives HIV positive persons important room for manoeuvre. Leaving things fluid and floating, such spaces serve the reconstruction of a positive social identity, and thus the establishment and regaining of respect.

Amy herself attributes her success mainly to financial resources: "Money is everything. It's because of money that Amy has become today's Amy." And she adds:

You know when you have nothing in life, people won't love you. (...) It's a question of position, when you have no means, the reactions to you are different compared to when you are in a good position, certainly financially. They consider everything you say and it's unthinkable to push you aside. (24.8. 2005)

Amy's story illustrates one of the fundamental principles of Bourdieu's (1983) theory on capital transformation: by means of economic capital she was able to strengthen, or rather regain, first her social and then her symbolic capital. Still, it would not be fair to reduce the success of her navigations to her financial achievements alone. Rather, her case illustrates the successful combination of various tactics that mutually complement and support each other – the payment of contributions, aspirational self-presentation, and flexible information management – that together helped Amy regain respect, though maybe not her name.

Navigating disclosure in the search for honour and respect

The long-term character of the present study elucidates the processual character of disclosure in its different, often ambiguous forms. I argue that people who are confronted with the question of how to speak about their illness do not orient themselves by the restrictive logic of 'either/or', but by that of 'both/and'. Thus, they open up a space between the dichotomy in such a way that the boundaries between what is said and what is concealed became blurred and fluid. While most scholarship focuses on disclosure as a discrete act that either exposes or silences (e.g., Klitzman et al. 2004; Maman et al. 2009; Salami et al. 2011), a process-oriented approach reveals many more variants along the continuum between these two poles, and highlights the importance of a context-sensitive perspective. People living with HIV choose various ways of talking about their disease, depending on suspicions that may already be circulating, the resources at their disposal and their position in the family. They navigate, simultaneously and in succession, different forms of disclosure, according to the setting and the people being addressed. In so doing, they find a broader space for agency and greater flexibility in their pursuit of social recognition.

Amy, for example, combines private silence, medical disclosure and public denial in parallel, winning the support of her family and regaining, if not her name, so at least the respect she had lost. To be sure, this heterogeneous management of information is

not in accordance with the usual expectations of those involved in health care politics when it comes to AIDS activists' public confessions. However, it draws attention to a most relevant aspect of disclosing processes: the primary concern of being considered a respectable person within the community.

Due to the far-reaching, socially disgraceful consequences of disclosure, 'gaining a confidant' holds its own challenges. This process is accompanied by various stages of doubting, pondering and studying, whereby a specific type of trust is of paramount importance because of its potential to ensure the integrity of one's name. Mariam said that in such uncertain matters it is best to first make sure that the ground is solid before you actually step on it. It is thus not blind trust that is at work here rather, this careful trust, as it is described by people living with HIV, is characterized by its association with protection and control. It is in this sense that I use the term 'embedded trust' to signify a kind of trust that not only embraces reflective as well as affective aspects, but also is fortified by associations of a material and institutional nature.

Since the beginning of the epidemic, it has become well understood that AIDS acts as a "revealer of the social" (Desclaux 2003: 4). In the context of disclosure, however, the social is not simply revealed – it first and foremost manifests its own intrinsic power. Decisions to confide in someone are positioned between conflicting expectations and priorities, alongside social necessities, as well as epidemiological, medical, and legal admonitions. As has become apparent in the statements and the practices of people living with HIV in Bamako, the issue of whether, when, how and to whom to talk about the disease is primarily guided by social criteria, and particularly by the desire to maintain honour and respect.

While several studies cursorily touch on this intimate link between disclosure and social recognition (e.g., Gilbert & Walker 2009; King et al. 2008; Le Palec 1994; Vuarin 1999), only a small number of contributions focus on this issue. One of these, a study conducted by Mfecane (2012) in a rural environment in South Africa, describes men's experiences of publicly disclosing their HIV status, and how this act enabled them not only to restore their masculinity but also to regain respect. This contribution, based on research in a context with a high prevalence of HIV, argues that disclosure has become much easier thanks to the new therapies and may even be a source of social respect. But it is certainly difficult to compare his findings with the situation in a low-prevalence country as Mali. More applicable are the findings from Moyer's (2012) research in Zanzibar, where prevalence is low, which give precious insights and paint quite another image. Moyer finds, however, that respect in Zanzibar is ensured by not mentioning the disease in everyday conversations and even by conscious acts of non-disclosure. In her case study of a young couple who are AIDS activists, Moyer elucidates how keeping silent can be a way to demonstrate respect as well as preserve individual and family honour. This form of 'respectful silence' is displayed both by the person living with HIV as well as their friends and closer acquaintances. The silence engendered by access to ARVs creates space for another important shift: the HIV-positive individual can abandon his/her role as a sick person, and focus instead on pursuing a 'normal' life in accordance with the local sense of honour.

In his seminal work about honour in African history, Iliffe (2005: 360ff) argues that the spread of AIDS on the African continent as well as the local reactions to it can only be understood through notions of honour. The vigorousness of honour cultures in Africa, Iliffe explains, obstructed the application of preventive measures and behavioural change. With this contribution, I offer an initial exploration in the local understanding of honour and respect as it is addressed in the context of HIV in Bamako, Mali. The study demonstrates that one's name – rooted in the Islamic concept of *adamadenya* – depends entirely on the perceptions and the words of others and can be eroded through multiple stages of suspicion and accusation. While a person's spoilt name can rarely be restored, respect, as a form of social recognition, is directly perceptible in every interaction, and can be reconstituted through appropriate arrangements. In this process family members play a key role. Without their assistance it seems nearly impossible to be appreciated as a honourable and respectable person in the eyes of the community. But as long as someone is not able to contribute to the family's livelihood, he/she will find it hard to be respected; there is an intimate connection between being, giving and belonging (Chabal 2009: 43f). Older informants express regret that, in modern urban communities, honour is increasingly shaped by financial means. On the other hand, as illustrated by the two examples of Mariam and Amy, an urban environment can also make it possible for people to procure the resources needed to appear as a honourable person. Without the earnings from the AIDS sector, through regular employment or *témoignages* payments, it would be more difficult or even impossible for either of these women to gain social recognition.

Last but not least, a legitimate question arises as to how AIDS work can profit from the insights presented in this essay. Even though my research is based on case studies and thus does not permit universally valid statements, it clearly shows the importance people place on remaining socially accepted in the context of disclosing processes. If we gain a differentiated understanding of local forms of recognition and their underlying criteria, we become more aware of social complexities, particularly with regard to the specific dilemmas faced by people living with HIV. While it may not be possible to transpose the present findings into immediate action, they can still inform future public health programmes with a basis for deeper understanding and further reflections.

Notes

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- 1 For reasons of confidentiality, all names used in this contribution are pseudonyms.
- 2 Kwansa, in his forthcoming doctoral dissertation about the management of HIV/AIDS in two Ghanaian communities, uses the metaphor of 'selling' for disclosing one's HIV status. Quoting a proverb, "Only when you sell your sickness, you will get medicine," he describes how people with HIV manoeuvre 'selling' their disease in different ways and to different degrees to get the best result for themselves without jeopardising their good name (Kwansa 2012).
- 3 Some contributions, arguing from the perspective of public health, point to the fact that reactions to disclosure are in many cases much more positive than anticipated (see Maman et al. 2003; Medley et al. 2004).
- 4 To facilitate openness between patients and their sexual partners, attending physicians volunteer to remain silent about their patients' HIV status, and offer to administer the test as if for the first time. By doing so, they take the responsibility for announcing the results, and are able to explain options of treatment and – most importantly – non-sexual ways of disease transmission, which helps to mitigate attributions of guilt.
- 5 As is explained by Bird and Kendall (1980: 14f), the dialectical tension between individual and group is expressed by means of the intersection of the two axes of *fadenya* and *badenya*. *Fadenya* (the unit of children begotten to the same father) refers to the axis of individual fulfilment and is associated with socially centrifugal forces, such as envy, jealousy and competition, while *badenya* (the unit of children born to the same mother) represents centripetal forces, such as solidarity, safety and trust that establish ties between the individual and the group.
- 6 This type of stigma transfer is discussed by Goffman (1963: 43, 64) from the perspective of 'togetherness' (courtesy stigma). In more recent literature, particularly in the context of HIV/AIDS, it is referred to as 'secondary stigma' (Brown et al. 2003: 51) or 'family stigma' (Kittikorn et al. 2006: 1292).

References

- Attaher, O.
 2005 *Pratiques de stigmatisation et de discrimination associées aux VIH/SIDA au Mali*.
 Université du Québec à Montréal: Mémoire de la maîtrise en sociologie.
- Attané, A. & R. Ouédraogo
 2008 Le caractère électif de l'entraide intrafamiliale dans le contexte de l'infection à VIH.
Science et technique, Science de la santé (Spécial Hors Série): 101-06.
- Bird, C.S. & M.B. Kendall
 1980 The Mande hero. Text and context. In: I. Karp & C.S. Bird (eds.), *Explorations in African systems of thought*. Bloomington: Indiana University Press, pp. 13-26.
- Bourdieu, P.
 1983 Ökonomisches Kapital, kulturelles Kapital, soziales Kapital. In: R. Kreckel (ed.), *Soziale Ungleichheiten*. Göttingen: Verlag Otto Schwartz, pp. 183-98.
- Bourdieu, P.
 1985 *Sozialer Raum und "Klassen", Leçon sur la leçon. Zwei Vorlesungen*. Frankfurt a. M.: Suhrkamp Taschenbuch Verlag.
- Brown, L., K. Macintyre & L. Trujillo
 2003 Interventions to reduce HIV/AIDS Stigma: What have we learned? *AIDS Education and Prevention* 15 (1): 49-69.

- Chabal, P.
2009 *Africa: The politics of suffering and smiling*. London, New York: Zed Books.
- Cissé, Y.
1971 Signes graphiques, représentations, concepts et tests relatifs à la personne chez les Malinké et les Bambara du Mali. In: CNRS (ed.), *La Notion de Personne en Afrique Noire (Colloques Internationaux du CNRS)*. Paris: Editions CNRS, pp. 131-80.
- City Mayors
2006 The world's fastest growing cities and urban areas from 2006 to 2020. Retrieved 12.5. 2008, from http://www.citymayors.com/statistics/urban_growth1.html.
- Corbin, J. & A. Strauss
2008 *Basics of qualitative research. Techniques and procedures for developing Grounded Theory (3rd Edition)*. Thousand Oaks: Sage Publications.
- Desclaux, A.
2003 Stigmatisation, discrimination: que peut-on attendre d'une approche culturelle? In: UNESCO (ed.), *VIH/SIDA Stigmatisation et Discrimination: une approche anthropologique*. Paris: UNESCO (Etudes et rapports, série spéciale), pp. 1-10.
- Do, N.T. et al.
2010 Psychosocial factors affecting medication adherence among HIV-1 infected adults receiving combination antiretroviral therapy (cART) in Botswana. *AIDS Research and Human Retroviruses* 26 (6): 685-91.
- Endress, M.
2001 Vertrauen und Vertrautheit – Phänomenologisch-anthropologische Grundlegung. In: M. Hartmann & C. Offe (eds.), *Vertrauen. Die Grundlage des sozialen Zusammenhalts*. Frankfurt/New York: Campus Verlag, pp. 161-203.
- Flick, U.
2005 *Qualitative Sozialforschung. Ein Handbuch*. Hamburg: Rowohlt Taschenbuch Verlag.
- Gilbert, L. & L. Walker
2009 'They (ARVs) are my life, without them I'm nothing': Experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa. *Health & Place* 15 (4): 1123-29.
- Gilbert, L. & L. Walker
2010 My biggest fear was that people would reject me once they knew my status ...': Stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health and Social Care in the Community* 18 (2): 139-46.
- Goffman, E.
1963 *Stigma. Notes on the management of spoiled identity*. London: Pelican Books.
- Goffman, E.
1967 *Interaction ritual: Essays on face-to-face behavior*. Garden City: Doubleday.
- Goffman, E.
1984 *The presentation of self in everyday life*. Harmondsworth: Penguin books.
- Hardon, A. & D. Posel
2012 Secrecy as embodied practice: Beyond the confessional imperative. *Culture, Health & Sexuality* 14 (Supplement 1): 1-13.
- Iliffe, J.
2005 *Honour in African history*. Cambridge: Cambridge University Press.

- Keppler, A. & T. Luckmann
 1997 Beredtes Verschweigen. Kommunikative Formen familiärer Geheimnisse. In: A. Assmann & J. Assmann (eds.), *Schleier und Schwelle (Band 1): Geheimnis und Öffentlichkeit*. München: Wilhelm Fink Verlag, pp. 205-20.
- King, R. et al.
 2008 Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS and Behavior* 12 (2): 232-43.
- Kittikorn, N., A.F. Street & J. Blackford
 2006 Managing shame and stigma: Case studies of female carers of people with AIDS in Southern Thailand. *Qualitative Health Research* 16 (9): 1286-1301.
- Klitzman, R.L. et al.
 2004 Intricacies and inter-relationships between HIV disclosure and HAART: A qualitative study. *AIDS Care* (16): 628-40.
- Kwansa, B.K.
 2013 *Safety in the midst of stigma: Experiencing HIV/AIDS in two Ghanaian communities*. Leiden: African Studies Centre, forthcoming.
- Le Palec, A.
 1994 Bamako, taire le sida. *Psychopathologie africaine* XXVI (2): 211-34.
- Le Palec, A. & H. Pagezy
 2003 *Vivre avec le VIH au Mali. Stratégies de survie*. Paris: L'Harmattan.
- Loubiere, S. et al
 2009 HIV disclosure and unsafe sex among HIV-infected women in Cameroon: Results from the ANRS-EVAL study. *Social Science & Medicine* 69 (6): 885-91.
- Luhmann, N.
 2000 *Vertrauen*. Stuttgart: Lucius & Lucius.
- Maiga, B., M.D. Bah & S. Castle
 2007 *Etude qualitative sur la stigmatisation et la discrimination des personnes vivant avec le VIH*. Bamako: USAID Mali.
- Maman, S. et al.
 2003 High rates and positive outcomes of HIV-serostatus disclosure to sexual partners: Reasons for cautious optimism from a voluntary counseling and testing clinic in Dar es Salaam, Tanzania. *AIDS and Behavior* 7 (4): 373-82.
- Maman, S. et al.
 2009 The role of religion in HIV-positive women's disclosure experiences and coping strategies in Kinshasa, Democratic Republic of Congo. *Social Science & Medicine* 68 (5): 965-70.
- Mattes, D.
 2011 "We are just supposed to be quiet." The production of adherence to antiretroviral treatment in urban Tanzania. *Medical Anthropology* 30 (2): 158-82.
- Medley, A. et al.
 2004 Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization* (82): 299-307.
- Mfecane, S.
 2012 Narratives of HIV disclosure and masculinity in a South African village. *Culture, Health & Sexuality* 14 (Supplement 1): 1-13.

- Miller, A.N. & D.L. Rubin
 2007 Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: People living with HIV/AIDS in the Sub-Saharan. *Qualitative Health Research* (17): 586-98.
- Mogensen, H.O.
 2010 New hopes and new dilemmas: Disclosure and recognition in the time of antiretroviral treatment. In: H. Dilger & U. Luig (eds.), *Morality, hope and grief. Anthropologies of AIDS in Africa*. New York, Oxford: Berghahn Books, pp. 61-79.
- Moyer, E.
 2012 Faidha Gani? What's the point: HIV and the logics of (non)disclosure among young activist in Zanzibar. *Culture, Health & Sexuality* 14 (supplement 1): 67-79.
- Mucheto, P. et al.
 2009 Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe. Retrieved 14.7.2012 from <http://www.panafrican-med-journal.com/content/article/8/51/full/>.
- Nguyen, V.-K. et al.
 2007 Adherence as therapeutic citizenship: Impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS* (21 Suppl.): 31-35.
- Peristiany, J. G. & J. Pitt-Rivers
 1992 Introduction. In: J.G. Peristiany & J. Pitt-Rivers (eds.), *Honor and grace in anthropology*. Cambridge: Cambridge University Press, pp. 1-17.
- Pitt-Rivers, J.
 1966 Honour and social status. In: J.G. Peristiany (ed.), *Honour and shame. The values of Mediterranean society*. Chicago: University of Chicago Press, pp. 19-77.
- Présidence de la République
 2006 *Recueil des textes sur la lutte contre le VIH/sida*. Bamako: Haut Conseil National de Lutte Contre le Sida.
- Roth, C.
 2004 Der mütterliche Schutz. Fünf Hypothesen zur sozialen Sicherheit in Burkina Faso. In: J. Schneider, L. Roost Vischer & D. Péclard (eds.), *Werkchau Afrikastudien 4*. Münster: Lit Verlag, pp. 113-32.
- Salami, A.K. et al.
 2011 Status disclosure among people living with Hiv/Aids in Ilorin, Nigeria. *West African Journal of Medicine* 30 (5): 359-63.
- Schneider, H., D. van Rensburg & D. Coetzee
 2007 Health systems and antiretroviral access. Round-Table Conference (University of the Free State Bloemfontein). 22-23.10.2007.
- Serovich, J.M., T.L. McDowell & E.L. Graftsky
 2008 Women's report of regret of HIV disclosure to family, friends and sex partners. *AIDS and Behavior* 12 (2): 227-31.
- Sow, K., & A. Desclaux
 2002 Vivre avec un traitement antirétroviral au Sénégal. In: A. Desclaux, I. Lanièce, I. Ndoye & B. Taverne (eds.), *L'initiative sénégalaise d'accès aux médicaments antirétroviraux. Analyses économiques, sociales, comportementales et médicales*. Paris: ANRS, pp. 169-78.

- Spitznagel, A.
 1998 Einleitung. In: A. Spitznagel (ed.), *Geheimnis und Geheimhaltung*. Göttingen: Hogrefe, pp. 19-51.
- Stewart, F.H.
 1994 *Honor*. Chicago: University of Chicago Press.
- Titilope, A.A. et al.
 2011 Psychosocial impact of disclosure of HIV serostatus in heterosexual relationship at the Lagos University Teaching Hospital, Nigeria. *Nigerian Medical Journal* 52 (1): 55-59.
- Vuarin, R.
 1999 "Le chapeau utile n'est pas dans le vestibule." In: C. Becker et al. (eds.), *Vivre et penser le sida en Afrique*. Paris: Karthala, pp. 433-53.
- Vuarin, R.
 2000 *Un système africain de protection sociale au temps de la mondialisation ou "Venez m'aider à tuer mon lion ..."* Paris: L'Harmattan.
- Waddell, E.N. & P.A. Messer
 2006 Social support, disclosure, and use of antiretroviral therapy. *AIDS and Behaviour* 10 (3): 263-72.
- Whyte, S.R., M.A. Whyte & D. Kyaddondo
 2010 Health workers entangled: Confidentiality and certification. In: H. Dilger & U. Luig (eds.), *Morality, hope and grief. Anthropologies of AIDS in Africa*. Oxford: Berghahn Books, pp. 80-101.