

Chapter 09

HIV DISCLOSURE: PRACTICES, KNOWLEDGES AND ETHICS

Corinne Squire

HIV disclosure is a technology that allows for treatment, and encourages the development of supportive social bonds, HIV subjectivities, and HIV citizenship and activism. HIV disclosure is also, though, related to criminalisation, to contact tracing, and to the stigmatisation and isolation of many people living with the virus. In this chapter, I explore HIV disclosure practices in relation to what is disclosed, who discloses to whom, in what circumstances, and by what means. I consider how these factors relate to stigmatisation or acceptance; isolation or inclusion; disbelief, minimisation, or affirmation; and ‘responsibilisation’, criminalisation, and activism. I also examine the relationship between disclosure and knowledge, since HIV knowledge is often uncertain or tied into networks of fears and hopes that may seem irrational and abjectifying. Lastly, I look at disclosure as a required moral narrative for subjects, undermined by both the impossibility of disclosing everything and the ambiguity of told secrets.

Disclosure is a contemporary technology that contributes to medical, social, political and personal governmentalities, that is, to the intersecting practices through which local, national and international organisations produce and regulate subjects and citizens (Foucault 1991). As illustrated in chapter one of this volume, it has many different realms of operation. In politics, it involves the making public of personal emotional, economic or social interests. In financial services, it requires the making known of personal economic interests. In government, the military and the police, it necessitates making public information about weapons and security when this information is asked for and when the state judges it

historically and politically safe to do so. In paid employment, disclosure entails statements about personal, emotional, economic, and, in the case of research and development, knowledge interests. In health, it connotes the conveyance of information about personal health, either to those who might reasonably be expected to have interests in it, such as family members, relationship partners, employers and health insurers, or to a more general public. In social life, disclosure often entails making explicit conditions that are unmarked but stigmatised, such as poverty, mental illness, sexual and gender diversity, illegal drug use, or criminal convictions.

Disclosure is a particularly modern, even late-modern technology. It comprises, generally, the transmission of knowledge from a realm understood as private, often personal, to one conceptualised as public. In certain circumstances, this process could be dangerous or unpleasant for the discloser or for others connected to the knowledge. It separates individual subjects from public life, while at the same time turning the personal into a perpetual object of public discussion. Citizenship becomes reduced to a private selfhood whose revelation constitutes the public realm (Rose, 1990). Disclosure also involves the dissemination of knowledge, a modern currency, the acquisition of which, like disclosure itself, is never complete. Moreover, knowledge is very often that of a socially transgressive past or present. The contemporary ties between public knowledge, self-knowledge and ethics appear particularly clear in disclosure technologies. Subjects are called to give an explicit account of themselves in order to enter into socio-ethical citizenships (Butler 2005; MacIntyre 1984). Here self-disclosure is inevitably incomplete, betrayed by the exigencies of language and of a subject which comes to know itself as it speaks itself into existence. It is also part of the language and knowledge of power within which ethics sits (Foucault 1977; Friedman and Squire 1998).

Disclosure also has many earlier precedents: in Christian confession, for instance (Manderson, this volume); in the continuing cathartic aspects of traditional health and spiritual technologies; and in histories of governmentality that have depended, in western capitalist states, on making visible subject characteristics in order to allow their monitoring and regulation by state, society and self (Foucault 1975). The condition of HIV is frequently lived with alongside stigmatisation, ‘othering’ and secrecy (Joffe 2006), and the dangers of revelation are often extremely clear. HIV therefore instantiates the complexities of disclosure in the case of health.

Knowledge, practices, and ethics

HIV is a virus transmitted, with some difficulty, via certain human body fluids. HIV disclosure concerns another kind of transmission, that of knowledge, usually in relation to HIV status, although also whether someone has been tested, is on treatment, or is ill. These disclosures can have medical, legal and social implications.

Disclosure in general passes knowledge, usually about persons – oneself or others – from one person to another. Knowledge cannot be understood adequately, however, if it is treated as unproblematically transmissible. Knowledge transmission, like HIV transmission, is complicated, affected by the state of what is being transmitted, who is transmitting it and who is receiving it.

One way to approach these complexities is to consider whether disclosure is simply transitive, and whether it always has an indirect object, the object disclosed to. When people describe disclosing their HIV status, they sometimes simply say, “I disclosed.” the object is left implicit. This omission could be treated as indicative of broader difficulties of saying everything about HIV. Again, people describing their disclosure sometimes include but sometimes exclude an indirect object in the dative case: the person, people or organisation

disclosed to. Of course, disclosure always does have such an object or objects: it is a dialogic process. However, the frequent omission of the indirect object also indicates wider problems of pinning down who is being disclosed to, and whether the disclosure has been received. In the light of these difficulties, it might be easier to view disclosing not merely as a verb signifying an activity, but also as a metaphor for a particular set of personal, social and institutional practices. In relation to HIV, for instance, “I disclosed,” regardless of its object and indirect object, often suggests personal openness. At times, it can have revelatory connotations that seem to provide a heavily moralised template for the passing on of knowledge that is rather different from straightforward knowledge transmission. Moreover, the knowledge that comes from HIV disclosure is frequently not what might be expected. More generally than disclosure, then, in this chapter I am concerned with practices, particularly practices of knowledge around HIV. I shall, like Manderson (this volume), move my discussion from practices, through knowledge, to ethics.

Like other illnesses, HIV does not just exist as a medical condition, but as a set of past, present, future and imagined, cultural, social and ethical practices. For this reason, HIV disclosure is never just about HIV or disclosure; it is particular kind of event, one that varies according to context (Iwelunmor et al. 2010). Stigmatisation and discrimination around the condition mean that disclosure has special salience: it has implications for work, relationships, children, sexuality, criminalisation, citizenship, social isolation and interpersonal violence. HIV disclosure has to be treated carefully by disclosers, audiences, and those who make policy about it.

Living with HIV is also not fully distinct from other everyday conditions of living. For many people, HIV disclosure is a regular part of daily life; for many more, a frequent topic of discussion or thought. This applies particularly where HIV is a high-prevalence condition, especially in sub-Saharan Africa; in specific communities, for instance, some city and rural

communities in the US, particularly for Latino and African Americans; among African migrants in high-income countries; and among gay men in countries at many income levels. In London, approximately one in twelve gay men is estimated to be HIV positive (Health Protection Agency 2012). Within such high-prevalence situations, HIV's hiding and disclosure within family, friendship and work networks are routine concerns. HIV is an everyday secret, like other health or socio-moral conditions, such as TB, cancer, syphilis, mental illness, illegitimacy, or criminality.

The contemporary extension of HIV treatment access to ten million of the 34 million people living with HIV, over 50% of those who need it (UNAIDS 2012), and the possibility and anticipation of treatment for others (Davis and Squire 2010), has contributed to resituating HIV and its disclosure as everyday. It has also changed the knowledge on which HIV disclosure trades, resituating HIV positivity as a 'long-term condition' (Health Protection Agency 2011) rather than a fatal illness. Ethically, too, the possibility of HIV treatment in the contemporary era has reframed HIV disclosure as easier, a moral call now less likely to involve personal and social suffering, and as less necessary and more contested, because if treatment has lowered viral load to undetectable levels, HIV transmission risk is low even if condoms are not used (Cohen et al. 2011).

(Not) researching disclosure

In this chapter, I draw on a 2011 study of HIV support in the UK, which included 47 interviews (half gay or bisexual men, 25% heterosexual men, 25% women). The interviews were not about disclosure, but they contained extensive material on disclosure (see also Squire 2013). Moreover, taking part in an interview explicitly about HIV is already a kind of

disclosure, to the interviewer and to oneself. In this way, the study implicitly presupposes disclosure as one of its interests.

Most interviewees were taking antiretroviral medication. Although they were doing well by the markers of CD4 count and low viral load, most had moderate to severe health problems. Disclosing their HIV status was therefore not the disclosure of an unproblematic, well-treated health condition: this is probably a minority experience (National AIDS Trust 2011). Around one-third of the interviewees participated in prior rounds of the study, dating from 2001 and in some cases from 1997 or 1993 (for instance, Squire 1999, 2003, 2006). The study therefore included a relatively large number of participants who were over 50 and who had considerable psychosocial and illness experience of living with HIV before the advent of anti-retroviral treatment in the UK in 1996. Their perspectives on disclosure were strongly affected by these histories of HIV as a fatal, untreatable condition, which for ex-IV drug users and gay men, killed large numbers of lovers and friends. In addition, around one-third of study participants were African-origin migrants, for whom disclosure had a doubled history within both the UK and their home countries. In Sub-Saharan Africa, treatment has only been available to the majority who need it since 2011, and prevalence of infection is much higher than in the UK. Hence, HIV disclosure has until very recently been the disclosure of a fatal condition affecting all families.

In this study, some participants were recruited by chain sampling. These included interviewees whose difficulties with living with and disclosing HIV were intense, and, on the other hand, interviewees for whom HIV appeared to be simply one of many of the conditions of their life, about which they were freely disclosing. Most participants, however, volunteered via websites and NGOs. Both people at ease with living with HIV and those who have strong dis-ease with the condition are unlikely to take part through these mechanisms, unless recontacted from earlier study rounds. Even in this case, some participants from earlier

rounds fell into these categories. One woman, first interviewed a decade ago, described herself as too beset with illness, only partly HIV-related, to want to participate again. Another prior participant who had moved away from her earlier HIV-related work said she did not want to spend time on a condition that was now a minor part of her life. In such instances, HIV has a powerful valency that people may not want to revisit via the disclosures involved in interviews. People more recently-diagnosed may have decided not to participate in the study because HIV was an unremarkable, well-treated and fully-accepted part of their lives. However, given the stories of stigmatisation and isolation told by recently-diagnosed people who volunteered for this interview round, the disclosures required in interviews may have seemed too overwhelming for some. Participants in this round can thus be inferred to include those who recognised some difficulties around living with HIV, but who were able also to countenance giving the disclosing self-accounts that interviews ask for.

The study involved practices or enactments of disclosure, within the interview themes of support, and within the self-story that such interviews generate (Riessman 2008). Interviews can be described as specific kinds of narratives, but they can also usefully be thought of, in relation to disclosure, as hybridising talk with friends; consultations with consultants; counselling sessions; assessments with professionals; and diaristic or autobiographical forms, or ‘talking to oneself’ (see for instance Kvale 2008). Interview disclosure draws on all these genres as well as on the disclosure genre produced by the researcher’s and the research participant’s understandings of research.

I used narrative analysis to address the interview materials, understanding ‘narrative’ broadly, as involving meaningful movements or sequences of symbols that build up meaning (Squire 2012, see also Andrews et al. 2013). I adopted this approach for a number of reasons. First, people often talk about disclosure via anecdotes or stories of specific events, or via ‘habitual narratives’ that generalise what often happens to themselves or others. Second,

within semi-structured interviews, prolonged, fragmented and complicated stories of HIV disclosure often developed across the course of the interviews, moving from well-worn tales of how disclosure does or does not work, towards more ambiguous narrative endings, adding complexity to disclosure. Third, a second etymological root of 'narrative' lies in knowledge itself: stories are means of telling but also of working towards or through knowledge. Treating the interview material as narrative alerts its readers to its active struggles for and with knowledge.

Disclosure practices and knowledge

Disclosure of knowledge about HIV status involves a set of particular practices, but it is also part of a constellation of life practices. Sometimes it is connected to technologies of external governance, sometimes to technologies of more intimate interpersonal or self-governance. Sometimes its practices are complex and hard to trace. In what follows, I outline some of these practices and their ambiguities as they emerged in the research.

Disclosure and governmentality

Within medical and social services, HIV disclosure is often planned and implemented by degrees on the basis of 'need to know', a term prevalent in social work discourse particularly, and taken over from military use (see also Vernon, this volume). Those who 'need to know' are usually identified as those closest to the HIV positive person, most intimately concerned with their care and with transmission-risk situations. Often, these people are advised or even required to know, particularly where ART is new and unfamiliar, where there may be bad reactions or side-effects, or a need for other care, or where they may be at HIV risk themselves. Professionals such as GPs, dentists, and chiropodists may not be required to know but may be thought to benefit from knowing. Yet even on this need to know basis, disclosure

is understood to be potentially problematic: family, friends and partners may reject you, professionals may not want to treat you. Quentin, a black African migrant living in London, in his 40s, diagnosed in 1995, had, like a number of other interviewees, found it very difficult to get a dentist who seemed comfortable treating HIV positive patients. He was also having considerable problems with his medication, which exacerbated his concerns about disclosing to his GP:

If you have problems to get GP, some practice they don't have dentist and sometimes teeth, dentist, dentist is very hard. And this how you become scared, I have to disclose as you for example go to/mhm/(doctor or dentist). This is when you say 'I have to disclose', for example when you go to dentist you have to disclose as far as I know some colleagues or some people the same as my situation they say if you disclose they don't give you appointment. They say maybe they give you longer time, you have to disclose or not because as far as I know some people some might, many, many people they say that to see a doctor take you a long time/mhm/This is our, sometimes at the GP, you describe, you have to disclose because some GPs they don't know about HIV and either they give you medication they don't know/Sure/If sometimes they give you medication, they can't, hah/Can't work/Yeah (laughs) can't work.

Disclosure to professionals is thus presented as necessary for treatment success but sometimes also leads to rejection or loss of confidentiality: "Sometimes you can see yourself with a red mark" (on the GP file), another interviewee, Queenie, a woman of African origin in her 50s, said.

Interviewees also registered requirements to disclose to lawyers and others dealing with asylum cases, and to those who needed to know because of the possibility of the criminalisation of HIV transmission, including lawyers and, most problematically, sexual

partners. Many interviewees had developed disclosure strategies to address this latter issue, such as immediate disclosure to people who interested them sexually, or serosorting online or via print ads or particular social venues (see Davis and Flowers, this volume). However, fears about the criminalisation of non-disclosure in intimate relationships and the disclosing potential of condoms themselves prevented some interviewees, such as Quentin, from having relationships at all:

And, hah, about the social lifestyle, to have partner (stammers) to have but or to have, this is another issue because you have to stick with sometime with the same situation. Otherwise it affects the law or how even when you have sex outside, you have to be conscience about that or if you have to use condoms, and sometimes when you meet [with] those condom and so on and so, they suspect you.

Disclosure was also reported as planned and performed, in relation to known protection policies at work and their alleged failures, with varying outcomes: from full disclosure working well across diverse work situations, to disclosure on employment applications resulting in failure.

Disclosure of HIV status is never really freely provided. It is always part of a contract in which things such as services, citizenship, relationships, personhood, are given back. However, the neoliberal regulation of individual biomedical HIV subjects via disclosure-based “technologies of subjectivity” (Ong 2006: 6, Rose 2007) had reached new heights when I undertook the interviews in 2011, compared, for instance, with the interviews in 2001. People brought me letters declaring their status officially, lest I not believe them. It appeared that HIV disclosure was popularly understood as a form of currency for people with few resources, and so needed legitimization. A more prevalent understanding of disclosure technologies for HIV positive people, however, was as very strongly ‘responsibilising’, as

Quentin described, again in relation to medical professionals, who, he explained, had the right to know and even not to treat:

You are worried if you reveal this disclosure, you may be, you say I prefer not to tell them and you are feeling you have to tell them, in order to protect them for me because sometimes it takes the opposite, better when they know you[r status] and may not treat you, I don't know, fairly or but that is why you should give them knowledge or lack of knowledge or information about them, because some(thing) is affecting us, them also.

In such narrative progressions, the governance of HIV by disclosure becomes internally, intimately felt and enacted: "If some(thing) is affecting us, them also".

Disclosure and intimate governance

At more intimate levels of self-regulation, HIV disclosure is a practice in relation to other HIV practices. For instance, it is planned in relation to how family members have reacted to prior experiences of HIV among people close to them, to what the partner thinks and says about condoms, to how friends discuss HIV when it's on the television or on World AIDS Day. In addition, family's, partners' and friends' rights are not exactly to know HIV status, but to the kind of intimacy involved with this status knowledge, without which something in these relationships would be seen as compromised or inauthentic (Davis and Flowers 2011). So HIV disclosure is also one of a set of connected practices around health, sexuality and reproduction, work and relationships.

Most research participants had plans for when to disclose in intimate relationships, and for when they would disclose to family members. The conditions were usually face-to-face meetings when they were in good health, although sometimes, if participants were generally well, they narrated plans to disclose only if they were getting ill. Obtaining

resources or citizenship status were also often preconditions within stories of planned disclosure, to allow participants to support themselves, not to trouble families, or to leave partners if they reacted negatively.

Sometimes these forms of HIV disclosure are externally regulated, for instance, via contact tracing procedures or health or social welfare professional strictures about who ought to be disclosed to and when, especially in relation to partners, ex-partners and children. Mostly, however, within participants' own narratives, disclosures were positioned within exchanges of emotions, intimacy and care. Queenie described a process of this kind in relation to her pastor. Although her story might seem to be about institutional disclosure, for Queenie, the relationship with the pastor was important:

Yeah, [the pastor] does [understand about HIV], because he even says "don't be shy talking about it, yeah. You can come for counselling, you can talk, even if you are ill in hospital". Like my pastor Henry, I told him. Yeah, yeah I told him but it took time for me to tell him, yeah. Yeah, I told him /yes/, he really supports me, even when I'm down or ill. Sometimes if he doesn't see me, he calls me, "are you OK, do you want someone to come and pray for you or talk to you?" Or even if I'm admitted to hospital he comes. I feel loved. There's no strings attached yeah, which is good. [Short exchange about not/telling congregation members.] Some people feel like they can't tell the pastor either/Yeah, yeah/. It depends on the relationship, that is why I said with me it took time. I was there in the church studying him, it took time for me, about three years, yeah. Then deep down in my spirit, I said oh yeah, I have to tell him now. I think I have to tell him now. I was ready, yeah.

This story demonstrates a common form across the interviews in its moves from intimate observation and evaluation, through disclosure, to acceptance and emotional

progression. In the later development of this narrative towards a retrospectively given origin in reflexive consideration, “deep down in my spirit,” we can also see the associations between practices of intimate, interpersonal governmentality, and self-governance.

Disclosure and self-governmentality

For the narrated self, disclosure may work as a practice that can release or heal. Some participants who described themselves as knowing about HIV and accepting it also described HIV knowledge, kept inside, as ‘eating away at them’. As a non-shared secret, it was corrosive. Such interviewees said that a disclosing openness enabled them to become ‘fuller’ versions of themselves, an approach that built on the processes of working through HIV acceptance through what might be called disclosure to oneself. Disclosure was thus articulated as part of a more general self-actualisation happening through the ‘testing’ route of HIV.

This is a relatively neutral description of self-disclosure and governmentality, marking the general psychologising of social lives (Rose 1990). From it, we might understand the processes in operation as restricting possibility within research participants’ lives. Such processes could be seen as a technology of what MacIntyre (1984) describes as ‘emotivism’, which reduces understandings of all social and political relations to personal emotions sequestered from full public comprehension but ciphered, regulated, and exchanged as a general currency. Within contemporary neoliberalism, the coding and management of subjectivities has become ferociously technical (Elliott 2013, Ong 2006). Nguyen (2010), for example, has described how international NGOs, especially in low-income situations, baldly require a particular form of HIV subject, self-aware, articulate, and emotionally resolved, if they are to provide treatment.

However, technologies of governmentality are not homogeneous in character. They can be part of progressive and activist framings of the pandemic. In stories of living with HIV, for example, “I disclosed to her/him” is often a testifying, ethically loaded moment. Such stories can expand the minimalised nature of neoliberal HIV subjects and the people around them, because within them, disclosure ‘tests’ oneself and the other person ethically. Something is, after struggle, confessed. As with all confessions, this one requires something of the person to whom confession is made, as well as of the person confessing. Disclosure is a dialogue, a disclosure *to* someone, not a transmission, a disclosure *of* something. Disclosure therefore makes a moral call as well as providing knowledge.

This self-technology is frequently tied into more collective articulations of HIV acceptance and activism. Disclosure is positioned in many HIV advocacy and activism contexts as a condition of action, a way of claiming space as a political biomedical subject, using but also of subverting the language of health and human rights (Mbali 2005, Robins 2009; Rose 2007). Disclosure thus becomes a part of a political technology of ‘speaking out’, similar to South American traditions of *testimonio* (Beverley 2004) against state violence, drawing on but not reducible to religious testimony. Where this politics of disclosure is entirely absent, one can often see real political difficulties. The fragmented and isolated situation of HIV positive people in Serbia and Montenegro, with no-one publically speaking out as and for people living with HIV, illustrates this well (Bernays et al. 2007). However, the contemporary invisibility of the HIV epidemic in the UK, frequently commented on by interviewees, offers a similar if better-resourced picture. One interviewee commented on the negative reactions, even ridicule, he had encountered online when he suggested a UK movement to wear ‘HIV positive’ T shirts of the ‘trademark’ kind that played a key symbolic role for many South Africans in owning the epidemic both personally and socially (e.g. Heywood 2009: 19). With a more positive outcome, Queenie described her contested but

finally successful attempts to affirm her own HIV status in order to testify to and help others. These attempts were themselves enabled by a micro-social world of intimate disclosures between friends and within support groups, and by a framing of disclosure as supported by faith:

So yeah, you have to be open, yeah, because you want to help this person, yeah. So, you have to be open and share your experiences ... that way you will help /yeah/ and after then you can still talk on the phone if it's possible, yeah. You can say 'how are you doing, any challenges, any problems?' You know, you try to refer to what I did; to me, I did this and this; try this one, try this one, yeah. ..This [HIV positive] friend [of my sister] took me to a support group. But I was shy to go there. I said 'oh they will look at me; they will point fingers at me'. He said 'no', he said 'look at me, I am positive'. And when I went in there, I saw happy faces. Then, I was asking, and she said 'no, everybody in here is HIV positive'. 'So do you think I will be like that one or that one?' I said, 'Look they are (feeling) strong and beautiful'. She said 'you will, you will', but yeah. So, I remember that day, the first day, it really empowered me, yeah. From then, I kept on going and going, as well, yeah. And my religion helped as well, yeah, my religion.

The complexities of HIV disclosure practices

Disclosure practices are not always as simple as they may seem. A disclosing HIV positive subject may have to negotiate his or her status as an HIV positive citizen at work, where it may have implications on types of activity and times of absence; in relationships, where it may affect sexual and reproductive practices, types of emotional connection, economic support, and interpersonal violence; and in the family and among friends, where a person may

be accepted like any other, or seen as a vulnerable child, a compromised parent, or a figure of contagion and terror from whom others withdraw.

HIV disclosure involves disclosures about a life and not just an HIV status. It may make sense of or cascade into knowledge about other medical issues, mental health issues, relationships, children, and bereavements. HIV disclosure for an asylum seeker in the UK, for instance, was also sometimes a disclosure about the necessity of leaving one's children in a country of origin with poor treatment access, and the impossibility of returning to them without citizenship status or money. For a person in this situation, the story of their children was often the most important one they told about HIV. Other interviewees, such as Quentin, told stories of stigmatisation and isolation, of 'dying twice' (Campbell et al. 2007a), which were, for them, the most significant aspects of HIV disclosure.

Even where treatment is accessible and successful, and friends are supportive, HIV disclosure may be constituted as an equation between life and 'being HIV' (see Davis and Flowers, this volume), rather than simply as a transmission of status knowledge. Sean, a man in his early thirties, characterising himself and his twenty-something boyfriend as HIV positive, presented this status as the entirety of their lives. They were relatively recently diagnosed, and both had had considerable problems with HIV-related illness and with ART side-effects. They were not, Sean said, "living with HIV;" they *were* HIV.

HIV disclosure can, vicariously, disclose something about other people's lives and hence disclosure does not affect just one person. If a person discloses their positive status, their whole family may experience associational shame. Queenie's disclosure of her diagnosis told her children, who ranged from primary age to young adulthood, something quite definite, not just about their late father's HIV status but also about his character:

My children they were very angry, yeah, they were very angry; especially, because they were accusing their father/The older children? /All of them, yeah. As soon as I had told them, they accused him because their Dad passed in 1997... So, when he died, he died when we were separated about two years ago, two years when he died. But they knew, because of the way he died. But with myself, I didn't know, because it was two years after I had left him ... So they were accusing their Dad, yeah, they were very angry. And, I ended up, I said "you know, there's no point because he's dead now, and I'm still alive. You just have to concentrate, erm, to concentrate, help me to pull through. And you, yourself as well, yeah, we have to work at this together; because if (you) are down and angry, it affects me as well, and I will deteriorate as well". Now, they are fine.

HIV disclosure also works by metaphor or metonymy to disclose other socially stereotyped aspects of self: sexuality, sexual history, children, moral personhood. The enormous rhetorical freight HIV drags around with it was early and well documented (Crimp 1988, Sontag 1989, Treichler 1999, Watney 1994). The power of these associations is indexed by the near inevitability that disclosure is followed by questions not just about health, but also ethically weighted issues about mode of infection and practices of containment.

The associations commonly attached to HIV disclosure in the UK are with homosexuality and bisexuality; sexual irresponsibility or transgression, for instance, sex outside a primary relationship; sex work; sex with people of African origin, bisexual or homosexual men; or intravenous drug use or sex with someone who uses drugs. For people recently diagnosed, HIV disclosure may also suggest credulity, carelessness, or mental health problems. Many interviewees disclosed their status during interviews in ways that told "how I got it" while also exempting them from such charges. One man in his twenties, for example, started the interview with the story of "my cheating ex;" another man in his thirties described

an earlier time of depression and intensive drug use. Queenie positioned the time and place where she likely became HIV positive as one when little was known about HIV. Ora, a white British woman in her thirties, emphasised, though a long account of the failure to diagnose her illnesses as HIV-related, her failure to fit her own and others' HIV risk profile, since she had not had sexual experiences or partners connected to the epidemic.

HIV disclosure can also *happen* indirectly, by association. These disclosures are manifold: medications in the bathroom or a bag; new habits of cooking and eating healthy foods; multivitamins in the house; keeping ART-related regular hours; less partying, drinking or doing drugs; continuing single status; new friendships with HIV positive people; work with HIV organisations; use of particular clinics or other services associated with HIV; conversations about HIV; the deaths or HIV-linked illnesses of partners, ex-partners and children; not breastfeeding; having a Caesarian section; having pneumonia, TB, meningitis, rashes, weight loss, shingles, herpes, or 'cancer'; putting 'rather not say' on a Gaydar profile under 'safer sex'; not using condoms; using condoms; or simply displaying, as Quentin noted, a new mood that your friends notice:

Even some people they start to ask me, 'Your skill is changed, you are not happy, you took', sometime (my friend) he ask me 'Why you took a lot of tabs'. I say this is because I have got - sometime I say, I have to lie. 'Yah, no, no! I have got some problem with my kidney or my (sugar) and the doctor', all those things.

This cloud of associational possibilities is not surprising, given HIV's own powerful symbolic weight. However, it compounds the nebulousness of disclosure practices, since not only what is disclosed, but also how disclosure happens, becomes diffuse, attached to the fearful recruitment of many different physical, biomedical, psychological and social signs.

The refusal to disclose is itself a disclosure practice. In many contexts, people work effectively as HIV activists without declaring their HIV status. Arguments around political or community solidarity can turn a disclosure requirement into something divisive, or that frame it as an external demand for inappropriate and possibly dangerous openness (Nguyen 2010). The responsabilisation of the HIV positive person to speak out could be seen as a parallel to criminalisation, removing responsibility from seronegative others. A number of interviewees narrated their own disclosure refusals in this way. In such accounts, non-disclosure was part of their practices of protecting or owning HIV knowledge themselves, and also a way of reframing that knowledge. Robert, for example, a white British man in his 40s, narrated this potentially empowering though sometimes highly stigmatising, non-disclosure as operating within HIV discourse, irrespective of status:

I was treated really badly by someone, I hadn't disclosed my status, but didn't do anything risky, and he made me feel like shit, and what was really great was a friend of mine who works in [HIV organisation] I phoned him up because he's a wise old sage, "I feel like crap", he said, like "tell him to fuck off", he said, "if he's so concerned about staying negative he should have said 'I'm negative', blah blah blah, from the outset". He said, "I'm fed up with", he's negative himself, my friend, "I'm fed up with these people expecting a positive person to disclose. If they're so desperate to stay negative then they should do it".

When successfully taking ART, there may be little reason, in relation to transmission, for a person who knows they are HIV positive and who is using condoms to disclose. Their risk of transmitting HIV, even if they do not use condoms, is low (Cohen et al. 2011). The risk of someone becoming infected by having sex with someone who cannot disclose because they are not tested and who is more infectious because not treated, is much higher; in the UK, 20-25% of those who are HIV positive do not know their status (Health Protection Agency

2012). At times, interviewees articulated this new aspect of medical technology alongside their rejection of the responsabilisation of HIV positive people for disclosure. However, interviewees taking ART, mostly aware of their own low transmission risk, were also deeply responsabilised and at times abjectified by their own non-disclosures, as Robert's repeatedly conveyed: "he made me feel like crap ... I feel like shit."

The failure of HIV knowledge among those who have not tested, or who have tested and not collected their test results, points to one absolute barrier to disclosure. In addition, some interviewees told stories about earlier suspecting their status, but not knowing for sure, or of disbelieving the test. Moreover, HIV disclosure is always disclosure of a particular knowledge of HIV; you may not disclose because you understand HIV as fatal; or as something that has killed many other family members; or as a condition that leads to social exile; or as a condition whose infectiousness, once treated, is medically unlikely but personally frightening.

Disclosure and ethics

As mentioned, disclosure is a socio-ethical imperative. Subjects have to give accounts of who they are and what they do in order to take up a social place. But in such an account, the person must speak from a position of knowledge and morality that they do not fully occupy, glossing over moral complexities and fixing themselves within an ultimately fluid language, as Butler (2005), following Lacan, notes. It is especially difficult to achieve this moral, disclosing, but necessarily tenuous self-account when one's position is also destabilised by HIV's physical seriousness, stigmatisation and uncertainties.

Treatment may seem to ease the moral ambiguities around HIV, but HIV's treatment-driven normalisation can also drive such ambiguities underground. Within the UK HIV support study, participants who were HIV positive, healthy, and well supported, often asserted

this condition as the current, normalised state of HIV (Squire, 2013). At the same time, almost all noted other, more difficult states of living with HIV, which they had heard about, seen, or experienced themselves in the past, and which can still happen, even with new drugs taken early. Sometimes they narrated these states in a still-normalised, medicalised way, as a form of accelerated ageing. At other times, they told more clearly pessimistic stories, for instance, of HIV-associated cancers, neuropathy, dementia, perhaps a chosen death, other feared and unknown HIV-related conditions, and stigmatisation and social exclusion. Current neoliberal restructurings and withdrawals of services intensify these subtextual negative knowledges. Even with improved services, however, such knowledges would likely continue unless HIV became much more medically manageable and socially destigmatised. Presently, they tend to make disclosure practices more complex, blurring what it means to disclose HIV status, and positioning such disclosure as more heterogeneous than a straightforward understanding of HIV as treatable and treated would suggest.

Disclosure reveals things kept secret, but secrets can never be fully revealed, and some things about HIV remain secret and cannot be shared or revealed (Derrida 2001). HIV status disclosure does not tell everything, yet it also tells too much. Disclosing can expose and depersonalise someone, taking things away from them. It gives them the name of the virus and substitutes that for their own name, their own person, even for themselves: “I am HIV.”

Derrida (2001) suggests that the condition of ethics is for people to be respected and acknowledged without having to tell everything – to be able to have a secret. Ethics requires us to recognise the other without knowing anything – let alone everything – about them. The kinds of proxy HIV disclosures discussed above, via for instance lifestyle changes, instantiate the proxy-ness of all HIV disclosures. Disclosure never tells us everything about living with serious, potentially fatal illness, and the uncertainties of it, nor about the possibilities of its limited effects, of being able to live well and healthily. The materiality of the condition,

inaccessible to disclosure practices – physical illnesses and fluctuations, daily drug regimes, the experienced effects of both, mental states of depression, anxiety and stress, as well as the healthy and unremarkable daily lives of many HIV positive people – index this incompleteness. This materiality, registered in the many fragmented and sometimes contradictory particularities of participants' stories, marks the inevitable failures of disclosure and the secreted persistence of things that cannot really be revealed.

Many activists argue that disclosure needs to be rethought for the new context of HIV as a long-term, perhaps soon a curable, condition. HIV transmission risk can now be reduced prophylactically, decreased by effective treatment, and removed in some cases by very early treatment. In this situation, the epidemic may best be addressed by focusing on living with HIV in the context of community and relationships, safety and prosperity, health and happiness, rather than in the context of disclosure and its associated fear. For some, though, a focus on 'status,' to which disclosure is tied, can be a hindrance. HIV disclosure should rather become part – a rather minor part – of a set of practices of a non-regulatory kind. It might even become irrelevant. These framings move either towards openness or towards the irrelevance of openness as a political strategy. In both cases, the framings position HIV knowledge and HIV's relations to subjecthood in a way that does not just secrete this knowledge in the bodies of the HIV positive, ready to be disclosed, but that moves it out into the HIV-affected world, taking it to every citizen, as the wearing of 'HIV positive' T shirts does. This critical disclosure perspective is not yet the place from which all the participants in the HIV support study seemed to be speaking. But it was certainly a position that they often tried to occupy.

References

Andrews, M., Squire, C. and Tamboukou, M., eds.

2013 *Doing Narrative Research*, 2nd ed. London: Sage Publications.

Bernays, S., Rhodes, T. and Prodanovic, A.

2007 *HIV Treatment Access, Delivery and Uncertainty: A Qualitative Study in Serbia and in Montenegro*. London: London School of Hygiene and Tropical Medicine/UNDP.

Beverley, J.

2004 *Testimonio: On the Politics of Truth*. Minneapolis, MN: University of Minnesota Press.

Butler, J.

2005 *Giving an Account of Oneself*. Bronx, NY: Fordham University Press.

Campbell, C., Nair, Y., Maimane, S. and Nicholson, J.

2007 'Dying twice': a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology* 12 (3): 403-16.

Campbell, C., Nair, Y. and Maimane, S.

2007b Building contexts that support effective community responses to HIV/AIDS: a South African case study. *American Journal of Community Psychology* 39 (3-4): 347-63.

Cohen, M., Chen, Y., McCauley, M., Gamble, T., Hosseinipour, M. et al.

2011 Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine* 365^[1], 6: 493–505.

Crimp, D., ed.

1988 *AIDS: Cultural Analysis/Cultural Activism*. Boston, MA: MIT Press.

Davis, M. and Flowers, P.

2011 Love and HIV serodiscordance in gay men's accounts of life with their regular partners, *Culture, Health and Sexuality* 13 (7): 737-749.

Davis, M. and Squire, C.

2010 HIV technologies. *In* HIV Treatment and Prevention Technologies in International Perspective. M. Davis and C. Squire, eds. Pp.1-17. London: Palgrave Macmillan.

Derrida, J.

2001 A Taste for the Secret. London: Polity Press.

Elliott, J.

2013 Suffering agency: imagining neoliberal personhood in North America and Britain. *Social Text* 31 (2): 83-101.

Foucault, M.

1975 Discipline and Punish. New York: Random House.

Foucault, M.

1997 The Politics of Truth. New York: Semiotext(e)

Friedman, E. and Squire, C.

1998 Morality USA. Minneapolis, MN: Minnesota University Press.

Health Protection Agency

2011 HIV in the UK: 2011 Report. London: Health Protection Services, Colindale.

Health Protection Agency

2012 HIV in the UK: 2012 Report. London: Health Protection Services, Colindale.

Heywood, M.

2009 South Africa's Treatment Action Campaign: Combining law and social mobilisation to realise the right to health. <http://www.section27.org.za/wp-content/uploads/2010/04/journal-HR-practice-heywood.pdf> Accessed 24.05.2013

Iwelunmor, J., Zungu, N. and Airhihenbuwa, C.

2010 Rethinking HIV disclosure among women within the context of motherhood in South Africa. *American Journal of Public Health* 100(8): 1393-9.

Joffe, H

2006 Anxiety, mass crisis and 'the other'. In Public Emotions. P.6, S.Radstone, C. Squire and A. Treacher, eds. Pp. 161 - 180. London: Palgrave Macmillan.

Kvale, S.

2008 InterViews. London: Sage Publications.

MacIntyre, A.

1984 After Virtue. Notre Dame, IN: Notre Dame University Press.

Mbali, M.

2005 TAC in the history of rights-based, patient driven HIV/AIDS activism in South Africa. <http://quod.lib.umich.edu/p/passages/4761530.0010.011?rgn=main;view=fulltext>
Accessed 25.05.2013.

National AIDS Trust

2011 Fluctuating Symptoms of HIV. London: National AIDS Trust.

Nguyen, V-K.

2010 The Republic of Therapy. Chapel Hill, NC: Duke University Press.

Ong, A.

2006 Neoliberalism as Exception. Chapel Hill, NC: Duke University Press.

Proudfoot, D.

2013 Irish mothers' narratives of living with HIV. PhD thesis, University of Bath.

Robins, S.

2009 From Revolution to Rights in South Africa. Oxford, UK: James Currey, with University of KwaZulu-Natal Press.

Rose, N.

2007 The Politics of Life Itself. Princeton, NJ: Princeton University Press.

Rose, N.

1990 Governing the Soul. London: Routledge.

Sontag, S.

1989 AIDS and its Metaphors. New York: Farrar, Straus and Giroux.

Squire, C.

2013 Living with HIV and ARVs: Three Letter Lives. London: Palgrave Macmillan.

Squire, C.

2012 What is narrative? NCRM Working Paper. <http://eprints.ncrm.ac.uk/3065/> Accessed 24.05.2013.

Squire, C.

2003 Can an HIV positive woman find true love? Romance in the stories of women living with HIV. *Feminism and Psychology* 13(1): 73–100.

Squire, C.

2006 Feeling entitled: HIV, entitlement feelings and citizenship. In *Public Emotions*. P. 6, S. Radstone, C. Squire, and A. Treacher, eds. Pp.202-30. London: Palgrave Macmillan.

Squire, C.

1999 'Neighbors who might become friends': Selves, genres and citizenship in stories of HIV. *The Sociological Quarterly* 40 (11): 109–37.

Treichler, P.

1999 *How to have Theory in an Epidemic*. Chapel Hill, NC: Duke University Press.

UNAIDS

2012 *Global Report: UNAIDS Report on the Global HIV Epidemic*. Geneva: UNAIDS.

Watney, S.

1994 *Practices of Freedom*. Chapel Hill, NC: Duke University Press.