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Dissimulation

Each day throughout the warm summer months he has put on a thick woollen jumper and nurtured a hot water bottle at his chest. He feels cold. Whatever he does, he cannot seem to get warm. He finds it difficult to concentrate at times, losing the thread of his thought, 'I've lost myself' he tells me apologetically mid-sentence 'I don't know whether it's the medication that makes me feel this way, because I am sort of dazed'.

James is soft-spoken, beautiful and dying from HIV-related cancers of the throat and lungs. James did not want anyone, including his estranged wife and two children whom he lived with, to know that he was seropositive. 'I just thought that the moment I mention this kind of thing, the whole family is going to shatter.' In the hospice where he had been admitted for a two-week stay for symptom control, James was passing himself off as someone with terminal cancer. So let's just say that James – he chose the pseudonym himself – is Kenyan and that he had lived with his secret for about 18 months before I met him.

London is the epicentre of the United Kingdom's HIV and AIDS epidemic. Nearly half of all HIV diagnoses are made in the city. The retrovirus HIV has hit Black African communities hard. For a decade or so they have accounted for over a third of those who find out that they are HIV positive. Despite advances in antiretroviral drugs (ARVs) that suppress the virus and stop the progression of disease, Black Africans are one of the groups least likely to access the drug regimens. Fear of stigmatization and insecure migration status are said to be some of the barriers to HIV testing and access to health care services.¹

To benefit from ARVs you need to have an HIV test. You should take the test early on in the disease when your CD4 cell count – white blood cells that are the backbone of the immune system – is *higher than 350 per cubic millimetre of blood*.

Those who are diagnosed late have a tenfold increased risk of death within one year of a diagnosis. In 2010, an estimated 50 per cent of those adults diagnosed in the United Kingdom were at a late stage of infection with a CD4 cell count of less than 350 cells/mm³. Late diagnosis was highest for Black Africans.²

Faces, numbers and surreal dreams can haunt you when you think of taking the test that will help you to access ARVs and the possibility of a longer, healthier life. In those moments, months or years you can find yourself drawn to the fates of those who are sick and dying around you, and in the city, hometown or village that you have left behind. You will try to develop immunity to the virulent gossip and judgements ‘This one is infected, can’t you see how slim she has become? She will die and no one will attend her burial’.³ You must be certain that the rumours that a seropositive diagnosis will lead to deportation are not true. And you should not be an undocumented migrant who may be refused National Health Service care or who will have to pay substantial hospital bills. If symptoms emerge, you will ignore them for as long as you can. When your condition gets worse, you may send for herbal remedies, perhaps bark powder or leaves from the Neem tree. Only when you are desperately ill will you seek emergency care.

At the end of 2011 an estimated 34 million people across the globe were living with HIV, about 30 million were living in low and middle-income countries.⁴

Sub-Saharan Africa accounts for 68 per cent of the global prevalence of HIV, with women and young people being disproportionately affected.

Population based health surveys suggest that less than 40 per cent of people who are seropositive know their HIV status.⁵

Figure 6.1 HIV, sub-Saharan Africa.

Courtesy: Nadia Bettega

Shock

James was diagnosed as HIV positive after noticing a thrush infection in his mouth. He thinks that he contracted the virus about four years before he

took the HIV antibody test. His memory of the test is vivid. It all began on a Sunday afternoon. Because it was the weekend, James could not consult his General Practitioner, so he had travelled by bus to the Accident and Emergency department of a hospital in the city centre. A nurse advised him to take an HIV test the next morning.

How did you feel when you found out?

I think the person I saw was quite nice, but it's such a horrifying experience being told that [...] yeah, I, I didn't know what to do [...] with myself or [...] whether to actually scream or cry or what. It was a terrible experience [...] because, you know, you are there, you are alone and here you are presented with this massive answer [...] which you didn't even want to know [...] and that's it. I just sort of froze [...]. I just thought 'It can't be me.'

To freeze like this is to be in the lure of simultaneous and opposing chemical impulses. Underneath the immobilization of shock, waves of adrenalin drive forward a movement from one state to another, from thinking *It can't be me* to a resolve of *It will not be me*. For James, this leaving behind of a self, who is somehow caught-up and at the same time is in flight, is a disturbing premonition and something familiar.

Some 20 years ago, he had left Kenya in pursuit of a better life, rising to meet each new demand, turning from one occupation to another, continually reinventing himself. Ultimately, he says, he found himself stuck, in the grip of another epidemic. It is not only viruses that cause a fever.

You get caught up into a certain syndrome and you remain in the same position. You come here thinking that you are going to make a fortune. You are going to study and after studying, you will find a job somewhere. Everything we think of is as if it is really made up for you. It's waiting. When you're in Africa thinking about Britain and all these big, you know Super countries. You always think that everything is there for you and that you can't fail because you hear the newspapers talking about countries of dreams, dream countries and say for instance in my position, when I came to Britain I thought as soon as I finish my education, I'll get a job. I'll buy a car. I'll buy this. I'll buy that.

That's not how it is. Things are completely different. You find yourself struggling to make ends meet and you get caught into a situation whereby you don't have enough money and yet you can't progress yourself. You cannot do anything to progress because you are trying to make money to survive. So things just stay there.

If what is *right* becomes more discernible when things go wrong, then the morality of James' hindsight⁶ as he evaluates his life, is one that is intruded upon by the canons of cultural tradition that have not let him forget how things *should* have been.

I felt caught because I didn't want to go back to Kenya and by then I had a wife who I was also trying to make work so that I could increase our revenue, and things were very difficult because you can imagine, you're a new person arriving in Britain, just to start working, whereas you should be treated in a different way, because she has just been newly wed and all those things were hurting me, because that's not the way it should have been. It should have been that I should have been set up and then when she comes I've got a house. I've got all the money really to look after her. It never happened that way.

The rub between the demands of tradition, disintegrating life-plans and what you are prepared to do in order to survive in the diaspora are never straightforward. Which customs matter? What can you let go? Which path is right for you? What might other people think?

If James found that money could eat into self-esteem, cultural tradition and family relationships when it was scarce, in times of greater plenitude he also became aware of how it could bestow and disperse social significance and standing. In London, when he had money, James was able to donate to cultural events and to funeral costs. In the 1990s, when the epidemic was at a peak, there seemed to be a funeral or more every month. James' beneficence was his emergence as a Somebody in both continents, maturing into an investment that doubled his sense of jeopardy. Practical matters loom large when James thinks about his family in Kenya.

I don't want to use the wrong words, but to my brothers and sisters I am an important person because I keep sending them money and if that disappears, it is a tragedy to them. So that is the fear within themselves, if this person dies, what will happen?

Officially recorded remittance flows to low-income countries are estimated to have reached \$372 billion in 2011, three times the size of official development assistance. The growth rate of remittances was higher in 2011 than in 2010 for all regions except the Middle East and North Africa, where flows were thought to be have been moderated by the Arab Uprisings.⁷

There can be cynical master plans behind faking an identity, but imposture in illness can be incremental, a day-to-day journeying where self-interest and a sincere concern for the good of others co-exist. Substituting one persona in favour of another requires courage and skill. It is also disease- and medicine-dependent. Some diseases, like skin colour or facial features offer more room and materials for masquerade than others. And some drugs, such as ARVs, can be so efficacious in controlling symptoms that it is entirely possible to mask and to even ‘forget’ that you have a disease.

But at the end of his life, the virus and its bodily devastations are only a part of James’ problems. The stigma that surrounds this disease and how it might affect his family, preoccupy James, driving him away from others, into a lonely phantom.

So it feels, just from what you’ve been saying, that this illness has been quite a lonely time for you.

It is, yeah, because it isolates you completely, and you don’t want anyone else, because it is like a taboo illness, because once people know that, you know, that you are this ill, the way they see you is confused. Completely different, I think, you know, people are too ignorant in such a way that, you know, they don’t understand properly. It makes me angry that people behave in such a way of ignorance that they don’t actually understand that it is just another disease.

Like cancer?

Exactly.

In the world of illness taboos and disease imposture, one person’s cancer is another person’s HIV. For Nusrat, a Pakistani Muslim, the decision to be open about her cancer was fraught. She knows from experience how quickly news can ricochet between London and Lahore and how in a matter of hours it can afflict generations of a family. Nusrat remembers those acquaintances that she now suspects were dying from cancer and who were hidden away behind closely guarded doors, excuses and half-truths – ‘We’ve come to see Auntie’ – ‘She’s sleeping’. They were made to disappear so that cancer and its threat of infecting and blighting the health of the heteronormative family could be deflected. ‘People feel that if others come to know about their illness, they won’t be able to marry their children off. Or people may think if the mother had cancer, then the children will also have it.’ Stigma, like culture and cancer, can be sticky and tentacular. It can also have an after-life, threatening the lives and the futures of others, so that the need for imposture can extend beyond a death. Louise, a hospice nurse,

We had a young Indian boy die of AIDS on the ward . . . I remember the father, they hadn't actually known he had AIDS, he, he had chosen to keep it from his parents and they had inadvertently found out from the ambulance crew um, who, who had berated them really for not telling them that he had AIDS. It was a terrible sort of chain of events, um, but they were also really distressed when he died because they couldn't have the coffin open at the, in the church, and, and they just really didn't know how they were going to explain that to all their extended family, er, it was just, um, they were, um that was a major hurdle, hurdle for his parents to overcome, 'What are we going to tell people if there's a reason why we can't have his coffin open?' It was, for them, that was like a very, very big issue [. . .]. I'm not actually sure how they resolved it though. I mean they basically told everyone that he died of skin cancer, um [. . .], and I think used that as a reason why they wouldn't have the coffin open, because it's, it's so distressing to look at, you know, and he would have been in a body bag and everything.

Barbara Browning, an academic, novelist and dancer, predicted some time ago that the progress made by white gay men's tactic of announcing their seropositivity was unlikely to translate in a future global context. ' . . . the strategy of volubility (Silence=Death)' Browning wrote 'was predicated on a fact of early AIDS demography in the US: the impacted community had a considerable economic, and so political base'.⁸ The politics of volubility has been limited cross-culturally, but the heroic figure of the proud HIV positive subject has also been recast by pharma developments, particularly the use of Highly Active Antiretroviral Therapy (HAART), impacting upon HIV activism among gay men and in how disease identities can be taken up, 'forgotten' or bracketed.

In March 2008, Cass Mann – *one of the world's then longest surviving HIV positive diagnosed gay men* – posted a video on YouTube *With Antiretroviral Drugs (ARVs), Does HIV Still Matter?*⁹ The film brought antiretrovirals into discussions of the increasing rates of HIV infection and sexually transmitted diseases among gay men. The implication was that the promise of longer life and a pharmacologically mimed asymptomology had impelled new illness identities leading to a decline in safer sex practices, denial of the risks of HIV infection, non-disclosure and new resistant mutations of the virus. Cass Mann's lilting Indian accent on YouTube does not temper his stark message. He tells his audience 'another danger of barebacking is if the person you are having sex with infects you with multi-resistant HIV. You are fucked. In more ways than one.'

As the sociologist Marsha Rosengarten has pointed out, what HIV is and its effects are informed by the unceasing 'traffic' of information between biology,

medical treatments, culture and how HIV is lived.¹⁰ HIV, Rosengarten argues, is not a single entity, but becomes the performative effect of value enfolded into evolving matter. What it means to be HIV positive – and therefore what it means to pretend that you do not have the virus – is constantly shifting and being reconfigured.

So HIV disease impostors and their accomplices walk through emotional and biopolitical minefields every day, surrounded by threats that are always regrouping. The danger is highly contagious, spreading out through social encounters, relationships and interviews. Impostors are difficult people to engage in conversation. They tend towards evasion, obfuscation and fast-talking, moving topics on before they become too close. Their sentences, straining at the seams with other things, kink and trail off. In my interview with James I tried to pick up on the clues and to fill in the blanks. But when there is no freedom to name or to tell a story I am not sure that there can be rapport or reciprocity.

Body heat

During my interview with James, I became entangled with his anxiety and nervousness. I felt small rushes of adrenalin and pinpoints of heat igniting in my face as we moved towards and then around incriminating words and topics. Our conversations became encoded. We talked about his *illness, the disease, the terminal condition*. This shared lacy language made a mockery of the recording of the interview and my assurances of confidentiality and anonymity. As the ethnographer Norman Denzin has recognized ‘Nothing is ever wholly private, and much of what occurs in public presumes confidential (private) understanding and agreements.’¹¹

‘Nothing is ever wholly private’. Yes. We both knew that. So we talked, and I now write, with non-synchronous shadows, labouring between what can be revealed and the husks of what must not be said, between the potency of this almost story and the forces that strangle it.

In my first attempts at making sense of what James was trying to tell me, I was too engrossed in the immediacy of the interview, too beguiled by the Western preoccupation with personal freedom, autonomy and reason. Potent contexts went missing. African masks that vanquish demons.¹² The trickster tradition of dissimulation and indirect criticism in Kenya as a response to national regimes of repression that flavours the work of writers such Francis Imbuga, John Ruganda, Ngugi wa Thiongo and Wahome Mutahi. And whole swathes of British colonial

secrecy covering-up the sanctioning of torture, castration and rape in Kenya during the Mau-Mau uprisings between 1952 and 1960.¹³

There is never only one secret. And we all have secrets. Some are so enduring that they are seemingly without origin, a part of the cultures and households that we were raised in. The unspoken presence of something withheld. Other secrets we acquire later, a response to the discrepancies and constraints that press in on us. And when someone wants to talk about their secrets but does not want to talk about them directly, we are in the world of secrecy. In secrecy there can be fear, but also what the British psychoanalyst Donald Winnicott has called ‘play’, an inventive intermediary space in which realities can be brought into the world of make-believe and can be experimented with – real/not real, me/not me.¹⁴

And although James often chose to talk in the third person and adopted the passive voice that erased the pronominal ‘I’, he was neither entirely silenced nor submissive to his secret. There was something more artful going on. Amid the ordinary conversational moves and turn taking, the densities of silence and hesitation that hung in the air were spooky and provocative. These demons forced me, and continue to push me to feel and to wonder about how things could feel so dangerous.

James’ omissions and innuendo corroded the distinctions between what is made public and what is withheld, what is safe and what is risky. And yet, despite all of the constraints, his muted story articulates and touches. It reproduced poetically in its silences, stuttering and slinky U-turns, the effects of dys-ease in his life, demanding a different empirical attentiveness and imagination. I have grown to think of the heat and pulses of adrenalin that I felt when listening and talking to James as fleshy text messages, small bodily interruptions and abbreviated inscriptions that forced me to feel how even the most ordinary and basic of human exchanges can become potentially catastrophic and life-threatening.

For a long time, I used to feel the pressure of thinking that to cover-up something of who you are because of fear and shame is to die a little; that being honest is wholesome and liberating, good for the soul. That was abstract thinking and Western reason. I was spending too much time with my head in the wrong books, ignoring what I know about the complicities of the heart and flesh, of living and dying in a morally buckled heteronomy, enmeshed with the warm needs and weight of others. So with James something unexpected tripped me up: how mimicry and passing can be their own palliative care, an intervention in suffering that can alleviate pain.

The word *palliative* is derived from the Latin noun *pallium*. There is some tension and play in its first meanings: to cloak, cover or protect.

This is not to overlook the damage caused by injustice, hatred and ignorance. Or to romanticize the lonely and insecure existence of disease impostors and the painful contradictions that they live with; how at one moment James tells me how proud he is to be a Kenyan, how he carries that pride deep within, how he will always regard Kenya as his home,

I still love it. I am going to go back, even if I am dead.

Can you tell me something about that?

I think it's just that I feel that I belong there, and I think that's a general consensus of most of us. We feel that we have no place here, that every person who is able must be taken back, buried back.

Then in the next breath when I ask about his relationships with Kenyan people in London, the ethnic identifications, the *we* and the *us*, fracture and dissolve, I receive something altogether more menacing: community as barbed and dangerous, predatory and two-faced.

I don't want to have anything to do with the Kenyan community here. With this disease they tend to actually prey on you, because as soon as people find out that you know, you have actually contracted this thing, they spread out rumours to the rest of the community which is quite damaging. So that's why most Kenyans don't want any other Kenyan to know about it.

Shortly before he died James told his estranged wife about his HIV. His fantasy of being buried in Kenya as a proud Kenyan was made impossible because of the medical administration that is required to repatriate bodies with HIV infection. At the time of James' death, several African countries were also refusing to receive the body of a seropositive person.

Community, like home, is an idea wrought from and too often squandered on life-long illusions. The fantasy and solace of Kenya as a final resting place for James could have been a last homage to the authority of cultural prescription. Or perhaps something entirely more visceral: a yearning in the blood to feel the caress of red earth, the smell of warm rain, to hear the *work haar-der, work haar-der* call of the ring necked dove. But I wonder whether I have been missing something. Whether in the journeying between the fissures of an idealized homeland and the bite of community, James was gesturing to a different space of belonging for some of us. Home not as birth right, continuity or safe enclave, but a condition sculptured from displacement and ambivalence, of that which falters

and fails. '*Home is our first real mistake*' the poet Ann Michaels¹⁵ has written in her haunting novel *The Winter Vault*, 'It is the one error that changes everything, the one lesson you could let destroy you. It is from this moment that we begin to build our home in the world. It is this place that we furnish with smell, taste, a talisman, a name.'

As I remember James sitting with me in that sun-filled room, holding tight to his hot water bottle, I think again about why he felt so cold and could not feel the warmth surrounding us.