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A Catch

When I was about four-years-old we were sitting eating a lunch of red rice ('samba') and curry at my Grandmother's home in Kandy. A local woman, black-skinned and spindly, sauntered into the house from the back veranda and asked for food, picking up some rice from a dish on the table with her fingers. I have never known the woman's name. She was known locally only as 'Kos Amma'. Kos is Sinhalese for Jackfruit. The name Kos Amma is itself a parody of *Kos Mama* the name given to the independence activist Arthur V. Dias, who pioneered a jackfruit propagation campaign in 1918.

Kos Amma was often drunk and liked to smoke beedis, small cigarettes of tobacco wrapped in a brown leaf. It was her habit to carry her Kos knife at her waist, at the meeting point of her faded batik redda (sarong) and choli blouse. The rumour was that Kos Amma had murdered her husband with the knife in a drunken stupor. She had then lit up a beedi and waited calmly for the police to arrive. I am not sure if this story has any truth to it; or how much of it I knew at the time. But when a drunk Kos Amma arrived at our table, I was terrified. The mouthful of rice that I had been eating seemed to stick. I was unable to swallow, caught in deep fear. My Grandmother admonished Kos Amma for frightening me and hurried her out of the house.

That event, the sight and sounds, the smells and tastes, the stilling of peristalsis, attached themselves to red rice. For some time afterwards whenever I ate the rice it would catch in my mouth and throat. I do not think of this catching, the small interruption of a reflex, as a literal regurgitation of a story 'about' Kos Amma. I have come to think of it as a bodily extension of some of the chaotic sensations of that lunchtime. There is so much mystery to percepts and affects. You will know all about this if you play an instrument or swim, or do yoga or

tai chi. Different movements, breathing and postures can slow, excite or raise to the surface sublime pressures and flows in the blood stream, muscles or internal organs as well as feelings and memories.

So I do not mean to colonize the unsaid and to suggest that bodies – breath, swallowing or skin – ‘speak’. Neither do I want to suggest that it is necessary to decode and translate this speech into a somatic story before we can respond to sensibility and its demands. As the anthropologist Thomas Csordas says the ‘non-verbal is precisely not language’.¹ We can miss something vital about the otherness of what is outside of words by treating the body’s lines of flight as analogous to language. ‘Reality is delicate’, the film-maker and writer Trinh T. Minh-ha feels, ‘My irreality and imagination are otherwise dull. The habit of imposing a meaning to every single sign’.²

Dirt

Family name: Lewis

First name: Maxine

Sex: Female

Religion: Baptist

Occupation: Retired nursing auxiliary

Primary Diagnosis: Bladder ca

Secondary Diagnosis: Lymphadenopathy

Family: 10 children (3 died in infancy)

In the last days of her life Maxine Lewis was a mess. Her face was streaked with the residue of mucus from her eyes, nose and mouth. A rancid musty odour encircled her bed. Professional negligence was not the cause of this neglect. Neither was staff shortages or budget cuts.

De nurse have time for me you know Yasmin. But I push er away every time she come wash me. She ball at me, an I don’t like people frighten me. I’m tired of people proddin an pokin at me all de time.

Prodding and poking is commonplace in the lives of cancer patients where the skin is as much a battleground as it is a protector. Skin is territory. A place of traction between the innards of the self and that which might engulf or save it. It becomes a site of puncturing, marking, impregnation, eruption, seeping,

stretching, burning and rotting. Patients can surrender themselves to the routine epidermal intrusions of medicine, giving up ownership of their skin. They offer up bared arms and hands without much thought. Some ready themselves to lift up clothing at the very sight of clinicians.

By the time someone is in need of terminal care, they have usually gone through the medical mill, enduring varying degrees of pain, intrusive investigation and treatment, dependency and disfigurement. They can be worn down, if not defeated by it all. The root of the word *patient* has various meanings connoting grief, need and hunger from which flow the associations of passivity and tolerance. Maxine could never be described as a patient. She was irreverent until the end, still able to find the humourous sides to her predicament. The recordings of our interviews resound with our laughter. The stories themselves were varied and captivating: marriage, arrival scenes, children and work. And between them all the solace, mischief and joy of civil disobedience. The cancer ravaged her body, but it failed to erase her spirit. Twice she had made daring, ridiculous attempts to escape from the confinements of hospitalization.

I use to walk up an down corridor with dis bag tingy attach to me. An I have it in my mind, I say 'I leave me tings dhere. All I want is key to get in an money to pay cab'. One of de time when I make to run away, two o'clock in de mornin, an de nurses at dheir table with de night lamp. They always notice me, going up an down, up an down. Sometimes they waves at me. So I walkin an I say to myself 'Pity you giving me a nice waving an don't know I'm on me way ome now'. An I reach far, you know. Oh my gosh Yasmin, I nearly reach de gate. I pass de canteen, I get to Casualty an I ear 'Maxine Lewis. Where you think yu going?' Oh my Lord, that urt me so much, I was jus about to get a cab an she say 'Where you think yu going?' An I say 'I'm going ome'. She say 'Home? You lucky you reach ere. Dhere is camera. Dhere is security guard. Come on an get back in your bed.'

Not unfamiliar with violation Maxine had become a warrior of sorts, through habit, volition or through forces beyond consciousness, it is difficult to say. On one of my last visits to Maxine after she had been taken into a hospice, she surprised me with a strange simile. She said she felt like a donkey. When I asked her what she wanted that donkey to do, there was no hesitation in her response. She wanted the donkey to buck and kick its heels in the air. And then there it was again, a twinkling in her eyes.

At the time I was visiting her, Maxine was the only person of colour in her six-bedded hospice bay. She felt the ripples of a disturbance to the sociality and

relaxed atmosphere of the bay with her arrival, noticing over the days how the small talk, jokes and exchange of glances and smiles did not extend to her bed. She suspected that the hospice nurses and volunteers had their favourites. She was not one of them.

Dey ave dtheir favourite an I'm not sayin it for a lie. It's true when dey would say 'Oh Lovie, Darling you wan your bedwash now' an tings like dat. Dat one dhere, from when I'm on dis ward she is working on dis ward. She never one day said to me 'Hello'. Never. An she come and with dat lady over dhere too to get tea, she give her first, 'Hello mi Darlin. Get up. Tea. Tea'. An she give er first.

Wards and bays are places of transit and transition, micro-habitats created by managers, institutional routines, statutory requirements, architecture and equipment. They are continually altered by the movements, leanings and expectations of those who are passing through. The geographer Doreen Massey believes that place is far from a stable entity. It is an event, open and porous, built up of accumulated layers of encounters that create a 'throwntogetherness' in 'the unavoidable challenge of negotiating a here-and-now'.³

If the spiky exclusions of the throwntogetherness of what was unfolding in the hospice bay pricked at Maxine, she did not tell her professional carers about what she was feeling. 'I never complain because I fed up you know, Dose girls no repec no black people. You have to fight for yourself'.

To complain or to talk about racism and other injustices goes against the grain of social convention, threatening the fantasy of harmony as a commensurable equality. It also contravenes the expectation that you should keep your troubles to yourself lest your oppression becomes oppressive to others.⁴

When you are vulnerable and dependent, when you feel that the care that you are receiving is relatively better here than in other places in which you have been a patient, it is especially difficult, if not impossible, to say anything about your unhappiness. The risk is that the unhappiness that you show will stick to you. You will be mistaken as the cause of discontent rather than its effect.⁵ You risk being seen as 'difficult'. Your care could be affected. Perhaps artificially enhanced rather than diminished, but affected nonetheless. At the end of life, organic pathologies are also at work.

In the last weeks of her life, Maxine's body was becoming more sensitized and unsettled as her disease progressed and she was given more drugs to relieve her symptoms. She began to become anxious when being touched and moved by the nurses. One day when she had been secured into a hoist that would elevate and then lower her into the warm soapy bubble bath that she loved, she refused

to keep her hands tucked in as she had been instructed. The hoist, as it raised her off the ground, made her feel unsafe and thingified *like a piece of meat*. In her anxiousness she began to practice a Gandhian satyagraha, non-violent non-cooperation, preferring to remain dirty than to be bathed. Days after the hoist incident Maxine was refusing all haptic care.

Compliance for the sake of making things easy never sat easily beside Maxine's combative will. Not even when she knew that playing nice could be a part of the brokering of small, but vital, survival deals. In exchange for acquiescence you can get things done. Those small extras. The bed-wash in the morning rather than at midday. Someone to comb out your hair or to help you to oil your skin. All of this was important to Maxine. From the photograph album that she showed me in her home during our first interview, I could see that she was a woman who liked to take care of herself. She had been someone who would coordinate a hat with her shoes and gloves, her lipstick with a brooch or a necklace.

Paranoia

So why would Maxine choose a dirty death? A disease related hypersensitivity? Have the touches that had kept her clean and comfortable – the swabs that wiped her face, the sponge sticks that moistened her mouth and lips, the hands that turned her – become painful and unbearable?

As the body faces a critical illness or disease state, a normal protective function may be to shunt a larger percentage of cardiac output from the skin to more vital internal organs . . .

Furthermore, the ability to tolerate pressure is limited in poorly perfused body areas.⁶

Mrs Lewis is irritable, showing increased sensitivity to minor discomfort, sound, and touch.

Paranoid ideas?

Maxine's nurses had recorded her heightened anxiety in her last weeks of life, alerting their colleagues of the need to take greater care when lifting and moving her. If she could have seen the handover notes Maxine would not have been surprised at the diagnostic label *paranoia*. I think she would have laughed. We both would have laughed.

Paranoia is a clinical term, whose symptoms include agitation and combativeness. These symptoms can suggest possible underlying organic causes that require monitoring. Living with any consciousness of racism and other social violations is also to live in a 'constellation of delirium', forever bordering on madness. So thought the Martinique-born psychiatrist Franz Fanon, writing in the book *Black Skin, White Masks*.⁷ Some racisms you can know and name for what they are. Others are more slippery and shape-shifting, wriggling in and out of substance and language, intermingling and dissolving into other energies and currents.

Maxine had noticed some of the to-ing and fro-ing between her body's intensifying sensitivities and her unsettlement in the ward. 'It's worse Yasmin when I have very bad migraines' she said after a story about how a nurse in the midst of responding to one of her questions had left her abruptly when another patient had called out to her. Not that uncommon in a ward you may be thinking. Not in itself evidence of racism. But small happenings gather meaning through their similitudes and continuities with other felt circuits. And with racism there is always a certain amount of doubt about what you are sensing and feeling. Doubt is the seed of paranoia and 'Our feelings become its truth' writes Sara Ahmed.⁸

Between these worlds of the solid and the ghostly you can encounter aggression, denial, guilt, shame and the most perverse of all: hurt innocence – 'I never meant it like that', 'I don't know what you mean'. Life will become more difficult – 'Why are you making things hard for yourself?', 'Lighten-up!', 'Don't take things so seriously'.

Racism's paranoia is not annexed from disease. Paranoia and anxiety at the end of life are part of a condition known as terminal restlessness. It can include paranoid psychosis or exacerbation of an underlying and unrecognized confusion caused by medication (opioids, anti-seizure drugs, steroids and anxiolytics), decreased oxygen, dehydration or untreated physical pain. The confluence between advancing disease, adverse reactions to psychotropic drugs and compromised renal and hepatic function can alter the chemistry of the body in ways that are impossible to disentangle from more habitual dispositions. And habits are themselves enmeshed in biochemistry, culture, place and their histories. Is that woman being 'difficult' and unreasonable because of her disease? Is she just angry and mean? Might her antipathy be a reasonable response to experiences that we have passed over?

In dying and in caring for those who are dying, there is a complex throwtogetherness of hypersensitivities, unpredictable in their hooking-up

and impacts. When somatic life involves violation the task of politics has been to explore, imagine and bring into language the connections between the body and social life, creating narratives that can articulate injustice and summon up new possibilities for living together.

Care practitioners also do this. Sifting through and considering different information and reasons as to why a body might express itself in the way that it does, interrogating care giving and organizational and professional cultures. The hospice social workers offer their insights.

- Jo: I kind of wonder about black people who have been in this country for a while, who have experienced racism on and off throughout their lives, that it becomes a kind of automatic response to any situation where they're powerless, which you are if you're being lifted, um, it's very frightening because if your experience is that white people cannot be trusted with you when you're vulnerable [. . .] then I think, your levels of fear must be really quite high, and that maybe, one argument for that would be 'Well then she's paranoid'. Another argument would be 'Well that means we have to be more careful'. But we have to know that when, if we're a group of white people with a black person, that they might have a history about their relationship with white people, and we either acknowledge that or we deal with it in some way.
- Jane: I think particularly when you're touching people, you know as nurses touch, and I think for black people who perhaps have never been touched by a white person, or only attacked, I think that must be particularly, particularly er, complex, you know, it really probably needs to be talked about really.
- Jo: And I also think that if you work on a shift on a ward for thirty-five hours a week with these patients who are continually dying, that maybe all your top level of tolerance and patience, you know you're up to here with it (her hand goes to the top of her forehead) and then if you take a difficult patient on top-
- Jane: Or somebody who lives too long-
- Jo: Or somebody who lives too long, or somebody who nearly dies and then lives, and nearly dies, or something's the matter with them going home or not, or else a difficult family. I mean all that makes it difficult for them and which is also, you know, I think that maybe their tolerance levels can get quite low.

In care although bodies are talked about and theorized, they must also be responded to – engaged, touched, listened to, moved and eased. Biographical

stories can help with the work of tending to bodies and their vulnerabilities but lived violation, hurt or trauma is not easily discernible. Good care must learn to work between what can be spoken and the chaotic sensibilities of the body that bypass language.

Comin throu the rye

Maxine's stories always seemed so fresh and unrehearsed to me, suggesting that she was not a woman in the habit of holding forth or of being listened to. Her tales were often pared down, told in paratactic syntax – short crisp sentences without the small conjunctions that help the Western listener transition from one narrative place to another.

So why I come ere in firs place? Cause of me stupid usband. Im come an ask me Mum an Dad for me marry. Im turn out to be sheep in wolf's clothing. I didn't love im. But you know, if a fella see you back ome an say they fancy you, you cannot court or go out. Im ave to go an ask for you properly. An even when him asks for you, you not to be fin out in the square, stan up talking to you.

Maxine did not want to leave Jamaica for London, but her husband had threatened to cut off his remittances if she did not join him. He was a cruel man who beat her and she could not bear to face his violence in a strange place, without family or friends for respite. But Maxine's parents were old fashioned. They had felt powerless to protect her, deferring to a husband's ultimate authority over his wife.

It's dem that put pressure on me to come. 'Dat is your usband. Where you bound, you mos'. You know, dey jus put it dat way. Back ome in de country, dey lif usband igher than God. I say to me Mum, me Granny, everybody, I say 'Would you like to be out ere an get a telegram dat he beats me to death?' Dey say they're praying. So I say, 'It doesn't matter to you if he beat me seven days a week'.

So Maxine found herself on an aeroplane bound for England. She wept her heart out during the journey. The other passengers must have thought that she was scared of flying. Her anxiety at flying for the first time was nothing compared to the fear of her husband's violence. What she did not foresee was the care that she would receive from the most surprising of places.

On one Saturday morning, after a brutal beating, Maxine went to her doctor's surgery. Blood was pouring from her nose and mouth. She told the doctor that

she had fallen down the stairs. After examining her and tending to the injuries, Dr Robinson agreed that Maxine could indeed have fallen down the stairs, injuring her mouth and nose like that. She suspected however that this was not the case. She did not lecture or interrogate. She gave Maxine a letter, instructing her to take it to Tower Bridge Court on Monday morning. The bold kindness of Dr Robinson seemed to touch Maxine. She did what she was told.

When her husband was summoned to appear in court, the judge asked him what kind of a person his wife was. Mr Lewis said that he could not find a better wife or mother for his children. He had never had to wait for his meals. The house was always clean and tidy. The judge noted that Maxine took her children to three different schools everyday, fitting in the school run and childcare around her night shifts in a factory, packing sandwiches.

Maxine felt that she got justice that day in court. But all was not well in London. Things were different then. Racist violence and abuse was at home in the streets. Twice she got licked. Once when she was seven months pregnant with Marcia. It was during the heavy snowfall of 1963. She had been with two of her husband's cousins when some boys in Rye Lane in Peckham threw a huge snowball at her chanting, *Go home monkey. Go home*. She would often hear the locution *Go home*. Today it was the word *monkey* that enflamed her. Today, she had had enough. Leaving the two men behind, Maxine ran after the perpetrators with her big belly and a fierce battle cry. The boys ran into a shop and cowered like the puppies that they were. The memory stings, yet Maxine's eyes sparkle with the small victory that has forever transformed the now vibrant polycultural spaces of Rye Lane – a street that has been a familiar feature in the lives of successive waves of migrants.

Every time I pass dat shop, an I'm in dis country from 1961, every time I pass dat shop, I stan up an give a lickle laugh, cause I remember dat's where dey run.

There are more and more studies that are turning to the exchanges of the urban street to understand how everyday encounters can have 'a bearing on how we test and learn with respect to one another' in the living out of multiculturalism.⁹ What is less amenable to multisensory notation and inventory¹⁰ is how the ghosts of the past can linger on street corners, at bus stops and in shops, intervening in the evolving feel of a place and its meanings.

Violent racism on the street was not unusual in 1960s London, Maxine says, but, do you know what?, it was black people who also did you down. A Jamaican co-worker at Dulwich hospital where Maxine used to work as an auxiliary nurse would wind her up everyday. Even though the work of auxiliary nursing

was demanding, Maxine enjoyed it. After two weeks of training and under the supervision of the matron, an auxiliary nurse was responsible for keeping patients and the wards clean, emptying bedpans, boiling eggs, cleaning patients' lockers, washing and polishing floors, emptying bins, cleaning toilets, clearing away vomit, urine, blood and faeces. Despite the job title, it was mothering work. Invisible and dirty, but often done with care and affection because back then you got to know the patients and their families.¹¹

One morning Maxine had suggested to her colleague that they take it in turns to clean out a blood stained area of the renal unit. The woman refused. She did not need the job or the money. She had two big houses in Brixton that were rented out to Jamaicans. Her husband collected the rent every Friday. The colour tax that local landlords charged new migrants had opened up opportunities for some of Maxine's countrymen. They had bought up properties and then rented out the dilapidated rooms to the new desperate arrivals.¹² One day, the woman's boasting and condescension got too much for Maxine.

She tell me 'You mos ave alf starving chilren for you to do dis work. I don't have to do it. My usband quarrel every day dat I going out to dis dirty job'. So I say to er 'Don't call me chilren names in your mouth.' 'But dem I've seen alf starved' she say.

Maxine punched her colleague in the mouth and split her lip. Violence at work was a sacking offence, yet Maxine did not lose her job. The young manager who knew her was sure that there must have been history behind the assault '*I say "Mr Baker, you can sack me now. I don't care. It's best I'm sack dan I ave to be wind up"*'. Maxine was given a warning and returned to her post. She remained at the hospital until she retired.

Patience

Maxine may have worked in a hospital for most of her adult life but she did not like being a patient. The nurses did not behave like proper caring professionals. They could bully people. They did not bully her of course, perhaps because several of the nurses in the local teaching hospital were from Jamaica. Sometimes they would all make jokes about Jamaicans together. They used to get along. But Maxine took offence when a nurse overstepped the boundaries. Sometimes a nurse would rouse a sleepy patient by peeling back the sheets and telling them to get out of bed, observing loudly that the patient liked bed too much. Maxine did

not like this sort of behaviour ‘Yu in ospital cause you tak sick, in dere to be care for. I mean it make a lot of people jumpy’.

If the lack of care in hospital was discomforting, Maxine was also growing intolerant of the tests that she had to undergo. Sometimes she would be eating a meal in the ward and a porter would arrive with a wheelchair to take her for a test. She had had several MRI body scans. Not that she was complaining about the scans. In Jamaica to have a scan would cost a lot of dollars. She had been through the scanner three times and had had a bone marrow test. She remembers every detail of the extraction of her bone marrow.

Imagine me, pure skin an bone, an dey didn’t even give me an injection to kill de pain. Dey come with dis trolley, a doctor an de needle. The mistake I mak is to look on trolley, cause the syringe is so big. Di man jus pull the screen roun an two nurse sat down, ‘Can we watch doctor?’ ‘Yes’ he say. ‘Yes’. An nurse say ‘Maxine. Maxine you can old us for support.’ So I was dis side. They stand dere. Ooh, I ave so much children, but I can’t remember one of dem pain ever feel like dat, Jesus, an they going down. I could ear di needle you know, an it going down an it still urt you know. Yes. An it going down. Den a bit of scraping, it going down an I hung on to de nearest nurse to me. When I finish with dose two nurse dey don’t have on no apron. Their apron was on de floor. Dey was sweating, panting an huffin, cause dey say dey never know a likkle person like me could grab anybody dat way.

Insight: Fully aware of her disease and the potential prognosis.

Over the months that I got to know Maxine, she did not speak directly about death. Her move from curative to palliative care was talked about through a change of tests, institutions or nurses, so that dying was somehow displaced from her body. During one of her hospitalizations, a staff nurse had asked Maxine if she knew anything about Macmillan nurses who have specialist skills in cancer and palliative care.¹³ Maxine said that she did not know what the nurses were called but she had seen them around the hospital.

I see dem, but I use to say ‘Funny init? Ow comes dey don’t wear uniform you know?’ To me dat’s better. Uniforms scare de daylight out of me, especially dem doctor white-coat. I ear about de ospice before, but I don’t know where it is. I was scared because white people, black people, everyone saying to me ‘You mosn’t go up dere.’

So Maxine was left wondering and pondering about what a hospice would be like. Then Kathy, a hospice nurse, came to visit her at home and arranged a

visit. A volunteer driver picked Maxine up from her home and drove her to the hospice. She was pleasantly surprised. The day was refreshing. She met and talked to new people and had a bit of a singsong. What she appreciated the most was the chance for some pampering.

I ave a lick – what’s it called? Lickussi bath wit all de bubbles an I should ave had me nails done de following week when I took sick. I got ague fever¹⁴. It make you shake and you ave dis fire. What you don’t know ague fever? It come from back ome, especial in de country. You will ear like someone aving a talk with me Mum an say ‘Oh Lord, Mrs Campbell, Jesus! The girl ave ague fever’.

The onset of the fever marked Maxine’s deterioration. When I visited her at home after the fever had set in, she was weaker and frail. She was admitted into the hospice a week later. She did not return to her beloved home.

The last time that I talked to Maxine at the hospice, she was sedated and woozy. Her thoughts drifted between the confines of the hospice ward – and whether other patients were eavesdropping on our conversation – and her father’s last words of advice to her before she left Jamaica.

When I was coming away, me Dad call me an say ‘I know ow you’s stubborn an I know you onest.’ An I tell him ‘Yes’. An I said ‘Papa why you keep telling me dese foolishness?’ An him say to me ‘Now you remember, you my biggest child. You going to Englan. Dat is a long journey you going on. I’m putting down good prior for you. If you in Englan an hundreds of you pack up into a room an dey give you one bottle of milk, don’t ask dem where they get de milk to give you alone. Don’t ask no question. Take de milk giving away, say “Thank-you very much.” Dat’s it.’ He was trying to tell me not to go an catch any trouble.

But trouble always seems to fin me.

Assessment and Guidance for Lifting and Handling Patients: Mrs Lewis is extremely anxious when being turned, needing gentle re-assurance as to her safety.

Syringe driver commenced.

Reduce BM monitoring to once daily.

Mrs Lewis’s restlessness has subsided. Move only for comfort.

It is always difficult to know how and where to begin a story. It is harder to know where it ends. It is the same with responsibility. And so I talk to a friend. The writing is not going well with Maxine I say. I explain that there could be organic causes in her resistance to care. But what if restlessness, paranoia and hypersensitivity are a body’s testimony to its past and not only a recent past?

I was beginning to wonder about the ways in which the body's activities can bypass subjectivity, reason and knowing, how sensibility can make a body into a work of art¹⁵ so that care must also become artful in its responsiveness. 'But,' and then there was a hesitation as I searched for the words. In the end I just say – 'But, there was this twinkling in her eyes when she told me her stories, even the stories of violence. I just can't seem to convey it.'

Then tell them about the twinkle she says.