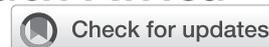


Three short stories of kidney disease in South Africa



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Everyone has three lives: a public life, a private life and a secret life. (Gabriel García Márquez quoted in Martin 2010)

Introduction

Leslie's mentorship and influence in my research cannot be underestimated. He was the person who urged me to undertake a doctoral study instead of only writing a short piece regarding my experience of kidney disease. He became my doctoral supervisor and the many conversations we had over the years about the theoretical and practical aspects of my work helped me to shape and refine my ideas. He gave me free rein to be creative, to discover and to play with ideas, something for which I cannot thank him enough – for this allowed me to find my voice and my self-belief. Thanks to him my PhD was exciting, enriching and opened intellectual doors for me.

I started using autoethnography as a methodology during my PhD on my own experience of narrative and identity in kidney transplantation (Richards 2012). Autoethnography is a qualitative research methodology where the researcher uses their lived experiences as part or all of the research. This is particularly useful for advocacy research about the experience of disability and other circumstances where the 'subjects' of research are often othered or silenced in different ways (Denshire 2010; Spieldenner 2014). They are seldom heard to speak or seen to act, but instead are spoken about and acted on. Seeing the complexity of marginalised people's experiences humanises them to mainstream people and this can help mainstream people with access to resources and power to change situations or to change how they treat those others (Ellis, Adams & Bochner 2010; Richards 2012; Sparkes 1996; Spieldenner 2014). It changes the power relationship (Pratt 1992). As people learn to understand each other better, this creates an environment where the chance for hermeneutic and testimonial justice (Fricker 2007) becomes possible. Furthermore, as a person with an education and training in research, I have a voice that other researchers may listen to.

Autoethnography can be conducted through different media, such as performance, visual art or creative writing. In autoethnography, the use of creative writing is called evocative autoethnography (Ellis et al. 2010); and this is what I chose to use. Its value lies in that it makes the narrator's experience emotionally and imaginatively accessible and immediate for readers (Ellis et al. 2010). Through this, readers may be able to imagine how they themselves could experience such a situation. Evocative autoethnography can also play with narrative constructs and narrative forms to change or trouble meanings and identities (Richards 2012). The use and value of creative writing methods in dealing with issues of health experiences and access also includes presenting information in a novel way that can be thought-provoking to a reader.

I had wanted to write about my own life-long experience of kidney disease to provide an insider perspective of a person living with kidney disease to counterbalance and enhance the more traditional research studies. For instance, my dissertation was written from the perspective of a long-term kidney transplant recipient reading literature on kidney disease and navigating the long-term vicissitudes of her condition. Many of the transplantation studies I read concerned the experiences of people who had received transplants a year to 5 years before. Long-term was considered to be 9 years. At the time, I had had my transplant for 20 years.

Following the completion of my PhD I wrote articles about different aspects of living with chronic illness and disability, for instance, the hidden shame and hardship of having an invisible condition that cannot be cured while working in academia (Richards 2019). My work always used autoethnographic approaches and blended personal writing with more traditional research writing to create a hybrid voice that represented my experience and understanding of a complex situation that has both an external appearance and an internal experience.

Note: The manuscript is a contribution to the themed collection titled 'Growing disability studies on the African continent: The career contribution of Prof. Leslie Swartz' under the expert guidance of guest editors Prof. Brian Watermeyer and Prof. Lieketseng Ned.

My piece of writing in this special issue differs from my previous work in that it is entirely creative writing, with no analysis. It also alludes to some recent changes in my condition. I chose to write it this way because I want to capture how I experience living with an incurable condition in a country that is medically under-resourced and where people every day die from a disease that cannot be cured but can be treated (Abd ElHafeez et al. 2018; Barsoum, Kahlil & Arogundade 2015; Davids et al. 2021). I consider the impact of the Soobramoney case (Constitutional Court South Africa 1997, 1998) through my personal, human response to it. This case was a landmark South African case where a man in kidney failure was denied dialysis because of constrained resources (Davis 2004). In my piece, I play off the gut-punch this outcome caused me, a person living with kidney disease, against the cold, emotionless legal documents about the case. The legal documents show how 'the problem' was 'solved' and assert that 'everyone' found this fair and satisfactory. But these types of decisions have terrible consequences for real people. Here are three parts of my story.

Story 1: Ghost body - A haunting

My story is written on my flesh. It's in my bones and in my blood. It's on my face; in my bushy eyebrows and my puffy cheeks. The signs are there for all to read, but most don't know how to. When I've told my story or written about it in academic terms, I have talked about how kidney disease made me feel and what I feared but *my* body has seldom been part of the story. It's always remained a dull haunting presence in the background just out of range. How could I tell the story of my chronic kidney disease without talking about what it did to my body? After all, who are you without your body? And yet I have been doing it for years. My story has been a story of interpretation – how I understand what happened to me – and somehow in all of this thinking, I made my body disappear.

But which body? My body is doubled. Not like a Matryoshka doll, but as if a different half-remembered body self was infused through my limbs, occupying the same space, eating the same food, breathing the same air, flinching with cold and trembling with fatigue when the stronger more corporeal body does not, shying away from needles that should no longer bother it, feeling that unquenchable ghostly renal thirst even though mine is long slaked.

Blood, sweat and tears

The disease, you see, was in my blood. It came from the outside, they said. But we never found out how. I was too young to remember, and my mother told me stories and I've read about it in medical reports. But my body remembers.

My body leaks its story through its own orifices and through those made from outside. Needles have left pits in arms, in neck, dents in thighs where the muscles atrophied from the jabs. It shies away from the needles still.

My body cries, not always from grief. My right eye waters because of a faulty tear duct. Both tear up in the sun, the cold, the heat. That might be because of the measles I had when I was nine. Whatever the cause, the salt tears always taste the same.

My body oozes life. It's always leaked. I replace the fluid all the time. You've got to keep the balance. Fluid out, fluid in – the opposite of what we were taught on dialysis to protect our hearts from drowning.

I've bled through my wounds, both big and small. I've bled from my nose. My bowels have bled. I've bled on my brain (twice). I've bled in the month. I've bled so much, I had to have surgery to stop it. My nose blood vessels had to be cauterised. Once a pinprick blood test took 20 min to stop bleeding. For the first 2 days after my transplant, I had to be packed with wadding and bandages to stop my operation site from bleeding. I could feel warm blood trickling down my right flank under the packing and seeping into the incontinence sheet. This was because of vitamin K to prevent clotting because I had a small stroke in theatre, a tiny blood clot in the part of my brain that controls the right side of my face. Thirty years later, the right side of my face is still weaker than my left when I get tired. I can feel it sag, like a silk bag with syrup in it, or melting like lukewarm wax down my bones.

I can feel my blood pounding in my throat, see my heart beating on the wall of my chest. Remember me, it warns. Remember my injuries. The hole that blew through my heart's wall when I was a baby. The virus that burned through me after transplant. My heart skips a beat sometimes, like a hiccup. Sometimes like the sea drawing back before a big wave. Usually it murmurs, but I can't feel that unless I have too much tea.

Blood in, blood out. Blood out, blood in. I've had three transfusions, but I only remember the last one. It was very slow, and the blood prickled as it oozed into me. I speeded up the flow and my skin erupted in bumps. My body didn't recognise the blood and shunned it.

I've leaked urine too. For samples, through a catheter and all by myself when my muscles grew too weak to keep it in. It flowed out if I laughed too hard or jumped too much. It was pale, like water.

And I've drained fluid from my gut cavity through a catheter for almost a year, four times a day, every day. I've run it in, and I've drained it out. It would run in transparent but bending light and would run out stained yellow with waste and garlanded with swirling egg white protein strands. I would cut the bag open and splash it into the toilet to flush it away. But I still peed water. I'd flush that away too.

Blood, bones and skin

My body hates blades. It has scars that run from left to right, up and down. There is a large Z across its stomach from

4 scars – my Zayin, my weapon of the spirit. There is a sun boat, a Mandjet, on its throat from where its thyroid used to be. There are tiny pockets from chicken pox and short snips from skin biopsies. Inside are gummy adhesions and a large scoop on the lower left abdomen from a surgery unrelated to my kidneys. In some places near my dialysis catheter site my fingertips can feel the membrane edges under the skin, scarified sharp and hard.

My skin is thin. My veins show silver-green beneath it. My capillaries show red. My bruises show in purple, grey, green and yellow. Small cuts bleed a lot.

My bones are thin too, after years of prednisone. Some are a third thinner than they should be at my age. They haven't all thinned at the same rate. Some of their honeycombs have bigger spaces. I've never broken anything. Yet.

But they used to be like lead, too heavy to drag around, a heavy metal clotheshorse that had little on it, that lost the clothes it was supposed to keep safe. If I could have parked my skeleton somewhere on campus I might have moved around more easily.

My joints ached. It started with my ankles – the left one to be precise. Gout when I was nine. I could feel it burning through my skin. Ten years later just aching in my large joints, no heat. Just a coldness that made me want to sit down and not get up. After the transplant and after the rejection episodes and after the massive cortisone blasts that went with them, my knees swelled so much that I couldn't bend them past 30 degrees. They felt like coals on fire. They still ache. I imagine that the bones swelled as they heated up and then cooled like lava into wrong shapes.

Skin and blood

Different shades of red. Reds. Metallic smell. Meaty smell. The last nosebleed I had made everything smell like a butchery. My blood got darker with time and (to me) more sluggish.

Crimson to ruby to wine. It was clotted currant jam. It dried burnt brick. Carmine or scarlet. Not hot enough for cinnabar. Not cool enough for mahogany.

Red is life and death, love and hate, passion. It is the colour of danger. In Ancient Egypt, it meant life, and also chaos. Sekhmet's blood lust turned by wine to slumber. Seth's rage against his brother, Osiris. Red is the colour of magic.

My inner ocean is red. My heart is the moon that controls its tides. Blood in, blood out. No. My kidneys are the moons, all three of them. They control the tide.

Or is it my lungs? Breath in, breath out. I used to fear falling asleep as a child in case I stopped breathing.

For a while I controlled the tide with dialysis: fluid in, fluid out. Four sterile bag changes every day for almost a year. The ritual for tide-controlling: Heat the bag, but not too much. After washing up to the elbows, anoint hands with pink Hibitane. Prepare the table and marble slab with acrid hydrogen peroxide, take the bag out of its sterile cover and place the bag on the slab. Hibitane hands. Open the bag. Hibitane hands. Undo the old bag and attach it. Hibitane hands. Run in the bag of clean solution. It takes about half an hour. Lie on the bed and watch it run in while I read. Control the flow with the catheter's V-track controller. Not too fast (burning), not too slow (cramps). Five or 6 hours later, drain out the fluid, now yellow and stringy with albumen. It takes about an hour and a half. Lie on the bed and watch it run in while I read. Fluid in, fluid out.

Skin and bone

Over the years I have become solid, from a faded, yellow ghost girl with dark rings under her eyes and ribs to count up into her armpits, to an ample, flowing woman, doughy arms, rolling stomach, milky skin. From hair that didn't grow for a year and nails that flaked to curly hair that I cut myself in lockdown surprisingly often. My nails still flake and tear.

I should diet. I have become quite overweight. And yet I don't. I eat as much as I can, of all the things I couldn't eat growing up. I've done it for nearly 30 years. Energy in – but little energy out. Who knows when I might need it? I feel stronger in my heavy body, rooted to the ground, not afraid of the wind. I can use my weight to push things. Inside my fat body is a thin woman who can never get enough food.

I was once so thin that I could have sworn I could see through my hands if I held them up to the light. I couldn't taste food. It had no flavour. I forced myself to eat, but I could not eat enough to prevent my flesh wasting away. My skin sank into the furrows of my hand bones. The knuckles bulged and the flesh withered. My collar bones pitched tents underneath my shoulders. I bruised if I sat on hard surfaces. I dressed from the children's department.

I can feel that ghost girl's eyes on me when I eat, hear her saying, 'I wish I could eat prawns. They are full of cholesterol, you know'. My arteries know.

Life and death

What will happen if my haunting body and haunted body become aware of each other? Will the solar and lunar barques collide or were they always the same boat? Will one of me die? Or will I descend like the green god, Osiris, to the underworld, re-membered, re-embodied, put back together again?

Since I was 2 years old I have often thought of how it will be when you die. Will you rot away, burn away, melt into

the earth? Will your body become a home for beetles and worms and your bones a shelter for birds? Or will you be ash and dust? I know how decomposition works. I've known for years. It used to disgust me, but I had to find out. I used to want to be cremated to avoid the swelling, the oozing and the putrefying. Now I think I'd like to lie down in the earth and go back to her, become part of the world again, seeping into the soil, feeding the creatures, helping make things grow.

Story 2: Thirst, a vampire story

Go down in the twilight. Go down to your room, to your bed in the quiet. In the cold shadows keep still. Lie down on your bed. Sleep again. Dream of blood. Dream of drinking blood, warm and thick, flowing over your tongue and down your chin. Gulp it down. It warms you up and makes you live again. Feel it on your palate and in your throat. Feel it hitting your stomach like a blessing.

Watch the people, but don't walk among them. You – the real you – can't be seen in daylight. You have learned only to be seen from a distance so that you still look normal and alive. You are not alive. Not dead, but not alive. You are undead now. It has been coming for some time.

Who do you see in the mirror when you look? You cannot see yourself. Do you see who you once were or who you will become? You learn to cover up the shadows under your eyes and to dust on the rouge for living colour.

Things don't taste like themselves anymore. Everything tastes of metal. Your throat doesn't want to swallow them. You feed off the memories of tastes and the dreams of blood. Your legs swell with water and the fluid creeps up to your lungs.

You can't wake up in the daytime and you are cold, so cold, even on summer days. Your flesh has melted off your bones. Your gossamer muscles are too weak to drag your leaden bones around.

You are tired, so tired.

Your skin is pale powder yellow now, shiny with sweat, and the insides of your eyelids and your gums are white. Your gums bleed often, so your mouth always tastes bloody, but not with the joyfulness of dream blood.

Your heart hiccups. When it does this the adrenalin spike makes you sweat, like a memory of fear, dimly remembered down a tunnel.

There are bruises on your arms and legs. Some from bumps and some from needles. The veins in your arms are scarred. Some scars are small, needle pricks in clusters. Different sizes because over the years your nurses and doctors have hit the same marks. One of your veins is sclerosed. It looks distended, perfect for puncturing, but it isn't. You know how

to read veins. You know yours from the inside. The medics always think they are helping you by picking it, because it's on your left arm and they see you are right-handed. But they aren't helping you and you know that having your blood taken from your right arm doesn't affect your writing. It's your hand that gets tired, not your arm.

The fog in your brain is like the twilight in your heart and the shadows under your eyes. Everything is grey.

You sleep like the dead, on your back, unmoving for up to 14 hours at a time. You used to want to fight to live, but now you realise that death is natural. Sometimes you look forward to it. Your body knows that it's dying. And yet, you remain stuck in the twilight.

You tell your mother and your friends that you are fine – but you're not fine. Do you smell like death? You can't tell. Your mother says your breath smells like rotting fruit. You carry mothballs in your pockets because you can smell them and you like the smell. It's interesting to your starved senses – faint, but interesting.

You dream of giant writhing maggots. They emerge from two septic-coloured yams on your bed. You fight the maggots with a sword, but each time you cut them they grow a new head. You get smaller as they get bigger. You can't win, but you keep on fighting.

Sometimes you sleepwalk. Sometimes you don't. You awake on your back, freezing cold, with your hands folded on your concave stomach, like a church effigy.

Story 3: Constitutional

I was sitting on the couch next to my mother one evening in 1997 watching the news on television (TV). Our living room was a cheerful yellow, with blue couches and five sets of bright windows looking out onto a warm evening where the sun hadn't set yet. Birds were roosting in the trees. Cars were coming home to their garages. Neighbours walked their dogs and greeted each other in the street. Workers were walking home down the hill to the taxi rank, calling to each other. It was the end of a long, hot day of this and that, some casual work, some social things, grocery shopping, household chores. Mom and I were working in a supermarket. She was manager and I did back-office admin.

In 1997 National Aeronautics and Space Administration's (NASA) Pathfinder space probe had landed on Mars, Princess Diana had died and the Kyoto Protocol had been adopted by a United Nations (UN) committee to establish a global legal framework on climate change. South Africa had a new constitution and a new national anthem. The Truth and Reconciliation Commission was in full swing. But there was one news item I had followed religiously through several months – The case of Thiagraj Soobramoney versus The Minister of Health.

Mr Soobramoney, who lived in KwaZulu-Natal (KZN), was petitioning the Constitutional Court for the right to receive dialysis in the state medical system. He could not afford to pay for dialysis, and he did not have sufficient medical cover to allow him private care. His plea for help had reached the highest court in the land and made it onto national news. Today his case is known as the first socio-economic rights case in the country.

I never met Mr Soobramoney. I learned from TV that he was a 41-year-old father of three teenagers. I learn today from the Constitution's webpage that he was 'a diabetic, unemployed man' who had 'suffered a stroke'. The page further observes that he was 'in the final stages of chronic renal failure and his condition was irreversible'. We are very proud of our Constitution; it has its own website. The webpage devoted to his case asks: 'In a constitutional democracy where the right to access healthcare is protected, can a hospital refuse a seriously ill patient treatment because of a lack of resources?'

After months of deliberation, it did. Mr Soobramoney had gone from the local state hospital to the High Court to the Constitutional Court. The arduous process had taken too long. In the end Mr Soobramoney had to be trundled into court in a wheelchair, where he drooped as the proceedings droned on around him. He was a terrible greyish colour and looked to me as if he was swelling from fluid retention and struggling to breathe. The news broadcast reported that Mr Soobramoney had accepted the verdict and that the outcome was a satisfactory one.

When I heard the verdict, I felt sick to my stomach. Although it was a hot evening, I went cold like years before when I was anaemic on dialysis. My stomach clenched into a ball of fear. South Africa was supposed to be a new country where all lives were valuable and everyone mattered.

Mr Soobramoney was sent home to die and 2 weeks later he did die. The news anchor reported with a tinge of dignified melancholy that he had 'passed away'. What would that passing have been like? A slow and terrifying death over 14 days as he drowned in his own toxins and body fluids. After that, his story did not make the news again. There was no follow up on how his three children were coping or whether there would be an attempt to address the inequity that had caused his death.

Instead, I heard a series of bland rationalisations about the public sector not having enough funds and that the Constitution 'must go on trying to resolve these problems'. Various parties expressed views that they were not responsible for changing the situation. Then radio silence. A quarter of a century later, I see no evidence that the problems have been resolved. I know that the vast majority of people in end-stage kidney failure are denied treatment in the South African state sector because of insufficient resources – not enough money, not enough equipment and not enough

dialysis technicians. Most people in South Africa only seek treatment when they are going into kidney failure because of insufficient access to medical care in the earlier stages and late-stage diagnoses.

On the Constitution's webpage I read that 'the Court felt his anguish'. Did it though? I am certain that the people involved felt some anguish and regret, but I am equally certain they did not feel Mr Soobramoney's anguish. How could they? If the only adjectives they used to describe him were 'diabetic' and 'unemployed' I doubt they really saw him. I can hear in how they describe his condition that they must not have had personal experience of kidney disease. After all, kidney disease is generally irreversible. It cannot be cured, only treated. And time is of the essence. It took months for him to be heard in the Constitutional Court, during which I doubt he was receiving any treatment.

But back to 1997. It was, as I mentioned, a warm evening. The windows were open, and a slight breeze fluttered the edges of the cream-coloured curtains. I had been well for 6 years. I had moved to the other end of the country away from Johannesburg and the years of struggling to survive. I looked normal. Down in the Western Cape no one I met knew that I had had a transplant. They just treated me like a normal person. I worked, I spent time with family, took French classes, walked around town to the shops, to the library, with ease.

When Mr Soobramoney had been denied treatment, I hoped a benefactor would take pity and step in – but none did. I knew, when I saw him slumped in his wheelchair, that it was too late. But still I hoped. For the months that I had followed the case in the media my stomach had been clenching tighter and tighter. Now it was a screwed-up ball of aluminium foil. Fear trickled through all my blood vessels and ran chilly fingers down my spine. It knotted my muscles in my arms and clenched my fists. I could hardly breathe. The summer evening had grown cold and dark.

Would that be me? Six years before, a doctor had told me that the transplant would likely buy me another 10 years. He seemed impressed by the extra decade; I had hoped for longer. Now, some years later and off dialysis after the transplant, I didn't have medical insurance because my job didn't pay enough. I was a state patient. I calculated my age in 4 years: 31. I weighed the odds: no other medical conditions. Maybe I could get back on the transplant list. It could take years, but I could do it. I'd have to move to Cape Town though because there was no dialysis centre where I lived. The calculating and weighing helped stop the ghostly fingers, but my stomach stayed knotted in a ball. And inside me I felt the ghost girl unfurl, like a dry leaf in water, stretch out her bony fingers into my warm ones, her heavy bones settled into my living bones, her cold pale flesh infused through my flesh and whisper a song through my blood that

tingled through each of my scars, pocks and needle marks. My Zayin was no defence against her. My sun boat sunk.

'Let us sleep', she said, our hands clasping over our cold bellies.

Closing remark

In 2024, after 33 years, my transplanted kidney failed suddenly and unexpectedly. I am now on haemodialysis three times a week for the foreseeable future. At present, my life revolves around dialysis. I am on disability leave from work and I seldom have the energy to do more than basic things. I have access to dialysis because I work in a job where I earn a salary that allows me to afford medical aid. I would not be able to afford dialysis otherwise. It's very expensive. How do I feel about my condition now? It's too soon to say how I feel, after the thing I always dreaded happened. In an online dialysis group I belong to, people are sad and angry about being on dialysis. They define dialysis as the problem. I, however, am grateful that I have access to it in a country where so many people don't. I have a chance to live, however peripheral and limited that life may be.

I am no more valuable or important than any other person, but my life is saved because I have resources. There is something fundamentally wrong with the idea that you get to live because you have resources, while someone less fortunate does not. We no longer have the death penalty in South Africa, but routinely people are sentenced to death because they are poor.

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