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VLAD SOKHIN

Plagued: TB And Me

By Jo Chandler
June 12, 2013

The greatest infectious killer in human history is making a comeback, morphing into new drug-resistant forms. While it is largely forgotten in wealthy nations, millions of people a year get sick from tuberculosis. Jo Chandler, to her surprise, is one of them.

IN THE WARPED CURRENCY OF WHAT WE DO AS JOURNALISTS, WORST IS BEST. WHEN WE WEIGH newsworthiness on the scales of disease and dysfunction, conflict and corruption, the bleaker the better. But for the reporter diving in, the maxim relies on a couple of critical perks of the job – the ticket home and the clean getaway.

The dismal conditions waiting at Daru Hospital back in August 2011 exceeded my saddest expectations. We spent some days poking around overflowing wards and diseased shanties for *The Age*, investigating the insidious reach of deadly, drug-resistant tuberculosis across Papua New Guinea. More than 60 per cent of the global burden of TB occurs in the Asia-Pacific region, and PNG bears some of the worst of it.

My notebooks were soon crammed with misery and my colleague, photographer Jason South, had collected pictures to break your heart. We couldn't get out of town fast enough.

But then our flight home failed to turn up on the crumbling runway. Feeling duty-bound, we add to the catalogue of sick and dying, though we already have more than our editors would want or our readers might endure. Jason goes to the hospital morgue and finds Edna Neteere wrapping her daughter in a shroud.

She was 19, her wasted body barely rumpling the sheet – consumed by disease, hence "consumption", as it was once so widely known. Her mouth is still drawn in a last grimace. Literature, history and the illustrious casualty list – several Brontes, Chekhov, D.H. Lawrence, Keats, Kafka, Orwell – might confer an aura of romantic dignity on TB diagnosis, but this young woman died "a terrible death," says the nurse. Likely those luminaries did too, albeit buffered by a few more comforts, like privacy and pain-relief.

Tuberculosis retains the distinction of being the greatest infectious killer in human history, claiming an estimated billion lives in the past 200 years. Its toll today is still second only to HIV (and it is the major killer of people with HIV). In 2011, 8.7 million people fell sick with TB. Edna's daughter was one of 1.4 million who died of it that year.

We ride with Edna and her family in the ambulance-cum-hearse, a hard-lived troop carrier, back to their shack in the settlements at the island's edge. One of the things I love about PNG is the raw, instinctive way relationships are recognised,

even fleeting ones. A handshake of greeting might graduate to the lingering clasp of friendship, of sisterhood, of bonds like motherhood. For the duration of the short ambulance journey Edna's hand weighs dry and warm in mine. She is bereft and silent.

Arriving at her home at 'Madame Corner' Edna's young son – distraught at the loss of his sister – is swept up in the arms of waiting grief. Several thousand people live in 'The Corners', rough villages of scrounged tin and timber, invisible borders demarcating the territory of each clan. They're cooking over choking fires; sharing an erratic, suspect water supply; shitting in holes – what option do they have? On our visit they're still burying their dead from a recent cholera outbreak.

They are residents of Western Province, on paper PNG's largest, richest landscape, many of them members of the Fly River diaspora (/web/20150318074509/http://www.theglobalmail.org/feature/up-the-fly-without-a-paddle/523/index.html) collecting royalties or compensation from the infamous, fabulously wealthy Ok Tedi gold and copper mine upstream. Nonetheless many are poorly nourished and dozens might share a room at night. TB thrives in such conditions.

On the map, all that separates their reality from mainland Australia is the narrow ribbon of Torres Strait, though the distance feels much wider. Locals can – and sometimes do – use banana boats to cross from one of the worst health systems in the world to seek treatment in one of the best. Such traffic is being discouraged by Australian and PNG authorities, stirring political sensitivities and medical controversy, which in part is why I have come.

Several mothers in the crowd cradle too-big children on their hips. One, Soba, introduces me to her four-year-old, Sawai. He had TB and now his legs don't work, but he's very clever, Soba boasts. His smile is sweet and incongruously joyful.

Some of the other children's limbs are shrivelled, their heads misshapen and eyes vacant in a way I have come to recognise. They are survivors of TB meningitis, the infection having found its way into their brains, rotting away physical and intellectual capacity. Their work-worn mothers must now be their legs, and when the tide is low they stagger through grasping mud, balancing babies, firewood and food supplies. The cruelties of this preventable, treatable disease are boundless.

Round about now my fortifying reporter's sense – delusion? – of mission falters. I feel ashamed for my intrusion; my questions sound vapid and hollow, drowned out by the keening. I don't feel so well. Jason empties the kina from his pockets and insists Edna take it – "for the funeral" – and we leave them to their mourning, their haus krai.

I'm relieved to get back inside the tall wire of the Catholic compound where we're guests, grateful for the security of the stroppy dogs that patrol the perimeter, for the comfort of a hard, narrow bed, and for the threadbare hospitality of the sisters. I'd really like to go home now.

Sometime in those few days, somewhere, someone coughed or sneezed or sang or laughed, spraying a cloud of invisible Mycobacterium tuberculosis into the air, and I inhaled. By the time my ride out finally materialises on the tarmac and I click my heels for home, it seems I have a stowaway. Eighteen months later, in March 2013, I am diagnosed with multidrug-resistant tuberculosis (MDR TB). Let's call it accidental immersion journalism.

MY UNINVITED GUEST IS WILY and resourceful, not unlike folk I've met who, like him, were born and bred in the unforgiving bayous of PNG's South Fly.

His DNA has evolved to remember and evade assaults from the pair of first-line, workhorse antibiotics that have worked so mightily to conquer TB in many parts of the world over decades – isoniazid and rifampicin. Until only a few years ago it was thought that only those existing TB patients who didn't take their medicine – because they couldn't access them, or because they refused or forgot them – were vulnerable to drug resistant strains. Now we know it spreads easily and invisibly in the air. My bug is a modern manifestation of an ancient plague that still has a few tricks up his sleeve.

"All the evidence suggests that tuberculosis is the archetypal, ancestral pathogen," explains Dr Ben Marais, a TB specialist at the University of Sydney. "It's been with us since we've been walking on two legs." In part, he says, it's the intimacy of hundreds of thousands of years of co-existence that makes TB such a formidable foe. It knows us too well. It's estimated that one-third of the world's population is latently infected with the TB bug.

"The TB bug is clever," agrees Dr Cathy Hewison, an Australian specialist based in Paris overseeing some of Médecins Sans Frontières MDR TB programs in 21 countries (https://web.archive.org/web/20150318074509/http://www.doctorswithoutborders.org/news/issue.cfm?id=2404) . "We haven't put enough time and effort into understanding it. We haven't put the time into having an effective vaccine. We haven't put the time into understanding the interaction between immunity and TB. We don't have good diagnostic tests. We don't have a rapid blood test. Our tests are failing us."

It's also capitalised on our selective attention. Members of my generation, in wealthy nations, may well recall that nana had TB and spent a couple of years in a sanitarium in the hills, but that's likely the last time the disease has touched our sphere. Most of the 1,000 to 1,200 TB notifications in Australia each year occur among immigrants and visitors. (Once I'm hospitalised my case, consequently, draws quite a crowd at Grand Rounds.)

TB is invisible because the people who suffer it are already on the margins, says Hewison. "They are the poor, the prisoners, alcoholics, refugees, Aboriginals, drug users, old people. And the drug companies forgot it because there is no money to be

made there," she observes. "I think we should blame it on a lack of interest."

Much of the armory health workers rely on – for diagnosis, treatment and prevention – is decades old. New vaccines loom on the horizon, but meanwhile the effectiveness of the standard BCG vaccine I got back in high school, which has been around for almost a century, is patchy. It may reduce disease among young children, but yields little protection when bacteria are coughed out by adults in epidemic situations.

Sixty years ago, with the arrival of effective TB drugs, "people probably thought TB was a vanishing disease, that it would be cured by social and economic improvement, that if we just improved standards of living it would go away. Which may still be true," says Ben Marais. But in many parts of the world the misery continued unchecked, and in 1993 the WHO declared TB a global emergency.

Twenty years later TB rates globally appear to have stabilised, even slightly declined (https://web.archive.org/web/20150318074509/http://www.who.int/mediacentre/factsheets/fs104/en/), and treatment programs rolled out over that time have saved (https://web.archive.org/web/20150318074509/http://www.who.int/topics/tuberculosis/en/) an estimated 20 million lives. But those statistics cloak a more sinister scenario. The disease has become deadlier and formidably difficult and expensive to treat. Drug-resistant strains of TB – like mine and worse, including a handful of cases so potent that they defy all treatments and conjure nightmare outbreak scenarios – are brewing and spreading in crowded, impoverished communities around the world.

The experts are deeply worried. For decades the response to global tuberculosis by governments in both wealthy and disease-endemic countries has been "complacent and politically neglectful", the medical establishment declared in a thundering editorial published in The Lancet in March. It pleaded for "visionary political leadership" to tackle the renewed TB scourge and devoted a special edition (https://web.archive.org/web/20150318074509/http://www.thelancet.com/series/tuberculosis-2013) to the cause.

"Rising rates of multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB threaten global control efforts in both developing and developed countries," The Lancet authors – Ben Marais among them – warned. The rise of drug-resistant TB and the ease of international travel means "the threat and range and spread of untreatable TB is very real … A major conceptual change and visionary global leadership are needed to move away from the conventional view that tuberculosis is only a disease of poor nations".

About the time this is published a young PNG woman diagnosed with still rare XDR TB dies in isolation (https://web.archive.org/web/20150318074509/https://www.mja.com.au/journal/2013/198/7/extensively-drug-resistant-tuberculosis-hovers-threateningly-australia-s-door) in North Queensland at Cairns Base Hospital. Then a Queensland mother, resident of Saibai Island in Torres Strait, just on the Australian side of the border, dies of MDR TB (https://web.archive.org/web/20150318074509/http://www.theaustralian.com.au/news/health-science/four-more-may-have-deadly-tb/story-e6frg8y6-1226647940583). At least four members of her family are infected. Queensland Health used to run a TB clinic on the island, and people would sail across from Daru for treatment, but it was closed last year. Australian and PNG authorities argued the money would be better spent investing in improved services and facilities in Western Province, but specialists in Cairns maintain a vulnerable frontier population has been abandoned.

I digest all this as I recover at home, still a little shocked when I hear the phrase "I've got TB" come from my mouth – and still adjusting to the horrified response it often elicits. My body is sore from surgery, and weakened and assailed by the mindblowing volume and variety of drugs coursing through unhappy veins. My partner is gentle and my children attentive and my parents worried. I'm profoundly grateful to every doctor, every nurse, and for every jab and tablet and almost every bloody cannula.

I have notebooks full of stories of TB patients who die seeing none of it. I summon up Edna or Sawai or any of the nameless, anguished casualties sprawled on grimy beds in a half a dozen countries. Or Christina, who had TB meningitis, and who we met in Daru.

We put her photograph on page one of *The Age*. Her mother was bathing her in a dish. She was six years old and weighed eight kilograms. Several readers rang the next day to complain about the picture, so you won't find it now if you Google the story (though you will see Sawai (https://web.archive.org/web/20150318074509/http://www.smh.com.au/world/aid-failing-to-prevent-pngs-health-catastrophe-20110908-1jzy6.html) and mother Soba). Christina's mother was praying for her to live but when I heard, months later, that she died, part of me was relieved – I wish I could find a better word.

The Lancet line also jars – "only" a disease of poor nations? So a failure to respond is excusable? Perhaps the authors are just more pragmatic and less squeamish than I about recognising, and exploiting, the powerful motivator of self-interest. So, shall we talk about me?

IT'S AGAINST THE ODDS that the M. tuberculosis should find a nook to settle and thrive within a healthy, well-nourished, vaccinated host like myself. Tuberculosis is, after all, a disease of poverty and proximity. As one doctor friend brightly remarked, "you won the lottery!"

Medical workers at the front line often seem blasé about the risk of infection. I've visited maybe a dozen TB wards, most in southern Africa and several in PNG, while researching stories, and only ever seen a minority of staff in masks. Given that I

merely waft around with a notebook and never deal intimately with patients, it doesn't occur to me to ask for one.

I was unwell when I returned from PNG in late 2011. It was all a bit baffling and I blamed it on anti-malarial medication, but then the symptoms settled and I forgot about it. But a year-and-a-half later I experience strange aches and occasional fevers and fits of violent coughing. One day I struggle to breathe at the top of a short flight of stairs, and figure I should see a doctor.

Shivering in a hospital gown, waiting too long for a verdict on a chest X-ray, I realise plainly something is awry. The radiologist traces the shadow of a large pleural effusion on the lightbox – fluid that is crushing my right lung, making me cough – and sends me straight to hospital with suspected pneumonia. I'm admitted and strongly advised by the emergency doctor not to Google "pleural effusion". Too late (https://web.archive.org/web/20150318074509/http://www.webmd.com/lung/pleural-effusion-symptoms-causes-treatments).

Over the next days come more tests, more scans, surgery to clean out the muck and biopsies for analysis. A chest tube is installed to drain fluid and I'm pumped with antibiotics that burn like fury as they flow through the cannulas in my wrists. I throw my first, and so far only, wobbly. And I worry, like sick people do. I'm questioned extensively about my travel history, and being a bit of a tosser rather enjoy recounting "Afghanistan and Antarctica". TB looks like a very long shot, the doctors say. They're vague on other frontrunners which, according to my research (curse the internet), include liver or lung cancer.

It takes a week for a test flagging TB as the likely culprit and that it is likely to be drug resistant. Everyone else seems appalled, but I'm just rapt it isn't cancer. I move to the Royal Melbourne Hospital where I'm put into the care of an infectious disease team and isolated. They're all tremendously reassuring and interested, though it's disconcerting that everyone who enters my negative-pressure single room must wear a mask – "just protocol".

As in the classic doctor's gag, there's the bad news – at least two years of aggressive drug treatment, including four months of intravenous drips. For ease of access a little dangling valve is poked in my upper arm and a tube nudged near my heart – a PICC line (peripherally inserted central catheter). It's a curious bit of bling but I love that it means fewer injections.

The good news? Tuberculosis is most commonly associated with the infamous hacking cough of pulmonary disease, when the bacteria inhabit the lungs and are unleashed on the unsuspecting via coughs and sneezes. But TB can grow in all sorts of places – stomachs, intestines, brains. My bug, at its own happy whim, has chosen to keep itself nicely corralled in the pleural sac around my lung.

As a result I'm not contagious. My partner, family, friends and the guy next to me on the train are all safe (my household is given mantoux tests, to be sure). Most blessedly I haven't endangered the newborn nephew I visited in hospital weeks earlier. The phone call to his parents, before the all-clear, is the hardest I have ever made.

Samples of my bug are sent to laboratories in Queensland and Melbourne and coaxed into growth . It will take two months for them to yield the details of my infection – what it fights off, what it will respond to. Meanwhile the strategy is to nuke the bugger with an arsenal of best-guess antibiotics, all tailored in a kind of chemical offensive to cover all bases and each other, although the doctors admit they are flying blind until the phenotypic analysis comes in - directly testing the grown organism against various drugs.

There's another option. Do nothing, and pray that I am among the one-third of patients who just miraculously recover. If there was even a moment of temptation it vanishes in the advice that I'd then run the risk of becoming infectious. Bombs away.

I'm stabilised, transferred into the care of specialists at Monash Medical Centre and sent home, where I'm visited every evening by nurses. They run a 30-minute IV from the magazine rack perched over the sofa; check or change the dressing on my PICC; record my 'obs' and take my blood; gently ask about my state of mind (scatty and often stoned) and bowels (don't let's start); check the jam-packed dosette box to be sure I'm keeping on top of my medication. And they are on my side, nagging the final-year-of-high-school son in the front room to Get Off Facebook. Without them I'd be months in hospital.

There are, of course, side effects to the drugs and enormous potential for surprising reactions. There are mundane complaints such as headaches and fatigue, thrush and diarrhoea, wild dreams and a terrible taste that overwhelms all food, ruins coffee and spoils the wine I shouldn't have. There's a perpetual ache in my chest (pleural scarring) which flares when I sigh or sneeze or laugh. My daily regimen now includes amikacin, cycloserine, pyrazinamide, ethambutol and moxifloxacin. I'm closely monitored for risks including hearing loss, eye damage, liver damage, kidney damage and, my personal favorite, psychosis. Of the latter, the kids want the doctors to explain – how would they tell?

So far so good on all fronts, whatever you might hear otherwise.

ACCORDING TO THE BEST GUESS of the World Health Organisation, I am one of an estimated 650,000 MDR TB cases worldwide (https://web.archive.org/web/20150318074509/http://www.who.int/tb/publications/global_report/). But the real reach is impossible to know because the technology required to diagnose it is so expensive and specialised that only five per cent of TB patients are ever tested for drug resistance, says MSF's Cathy Hewison.

The vast majority of patients will never have a nurse drop by in the evening with their IV. They live in places like The Corners in Daru, PNG. That they might ever realise even the most pared-back version of my treatment is unimaginable. Their prescriptions will not be tailored to their conditions. They will likely suffer toxic effects – maybe lose their sight or hearing –

from drugs that do them no good whatsoever, and miss out on therapies that work. If they have access to a program at all "the doctors might feel better", says Hewison, but such regimes deliver little prospect of improvement to the patient.

In nations such as PNG, Australia's closest neighbor, where TB has raged largely unseen – thanks, until recently, to the lack of diagnostic tools – and often unchecked, fragile health systems are already overwhelmed by the burden of the disease. When epidemiologist Dr Emma McBryde, from Melbourne's Burnet Institute, conducted a landmark survey of hospitals and remote aid posts in PNG's Western Province last year, she was stunned to find almost every bed taken by TB, the disease sucking up scarce resources and limited capacity, marginalising other urgent health concerns. Some nations – notably South Africa - are considering bringing back sanatoria (https://web.archive.org/web/20150318074509/http://abcnews.go.com/blogs/health/2011/10/25/drug-resistant-tb-could-bring-back-sanatoria/) to confine the sick and contain the spread.

The McBryde report (https://web.archive.org/web/20150318074509/http://www.ausaid.gov.au/countries/pacific/png/Documents/png-tb-evaluation-of-risk.pdf) estimated the prevalence of registered TB in Western Province at about 500 cases per 100,000 people, on par with acknowledged international hot spots such as Mozambique and Cambodia. "Nevertheless, the true incidence of TB is likely to be even higher due to poor access to health care and poor rural health services in the region," she reported.

While Western Province has attracted wide media interest and huge investment by AusAID and other agencies, that's more likely due to political sensitivities and geographic proximity to Australia than to its situation being any more deserving or its systems any more burdened than some other parts of the country. Experts say that while Western Province is likely to have one of the worst TB profiles in PNG, there are other critical hotspots, including in settlements in the major cities .

Research will be presented at a TB symposium in Melbourne over the next two days indicating a prevalence of more than 1,000 per 100,000 in adjacent Gulf Province – second only to Swaziland. (The data is in review pending journal publication.)

"I think we need to be worried," Dr William Adu-Krow, the WHO chief in Port Moresby, said when I interviewed him last December (three months before my interest in the subject became more personal). WHO's own updated and still-to-be-published findings were also "very dramatic", he said, ranking PNG amongst the "worst in the world".

"Papua New Guinea is one of the few countries with a prevalence rate of more than 500 TB cases per 100,000 population. It was 534 in 2011, which is more than triple the regional average of 138 and the global average of 170 in 2011."

The arrival of new diagnostic technology just last year is signalling a drug-resistant TB epidemic which is, he says, "off the charts" in Western Province and neighbouring Gulf Province. About half of the TB-positive sputum tested in Daru Hospital after the arrival of a geneXpert diagnostic machine last May was showing as multidrug resistant (MDR) TB.

Those early findings "gave everyone a shock", though they were likely biased in that samples from the most suspect cases were the first to be tested, says Ben Marais. "But overall … these are alarming numbers, and cases are far more widespread than anticipated."

A FLASH NEW TB WARD, built with AusAID money, will be opened at Daru Hospital sometime this month, undoubtedly with much fanfare. It's part of a substantial portfolio of investments in health in Western Province – by Australian taxpayers (more than $30 million in that province alone), The Global Fund (https://web.archive.org/web/20150318074509/http://www.theglobalfund.org/en/) and aid agencies led by World Vision – aimed at improving what were recognised as dire conditions.

When I visited in August 2011 the hospital wards were derelict and overcrowded. There were too few nurses and drugs were in short supply. There was no doctor to be found. The X-ray machine was broken. "Poor old South Fly," one veteran Australian aid official told remarked then, "seriously, God forgot them."

Much has changed. As well as the new specialist TB ward there's also a new X-ray machine and a coveted geneXpert diagnosis machine to quickly identify drug resistance. One of the most admired and formidable figures in PNG health circles, Sister Joseph Taylor – a Yorkshire-born Passionist nun and surgeon – has taken charge of the hospital. AusAID money has also gone into securing two specialist TB doctors, improving and extending community health programs and outpatient support, running a sea ambulance to access remote communities and improving internet access and communications.

Cure rates for people with TB in Western Province have improved from 45 per cent a year ago to well over 60 per cent, says World Vision PNG Country Director Dr Curt von Boguslawski. He gives much of the credit to programs extending support inside communities like The Corners – health workers reaching in to locate and support people with TB, making sure they take their medicine. "There is still a lot of work to be done – 85 per cent is the world standard.

"There is a lot happening. It's on the agenda now, people are talking about it," he says. "At times it is very frustrating … [but] for the first time we have some hope. For the first time in PNG we have country-wide reporting of TB cases. And for the first time we have secure access to TB drugs."

Less optimistically, the capacity of organisations such as World Vision and others is largely determined by the machinations of the wider realpolitik. Support from The Global Fund – which pools private donations and state money, including from Australia, and is now the world's largest financier of HIV, TB and malaria programs – for PNG programs has been precarious, but a $13 million grant has now been locked in for the next 18 months.

The Global Fund is itself strapped for cash. It wants the PNG Government, enjoying the windfall of a resources boom, to channel more of its own money into the critical task of tackling TB. Meanwhile an audit has undermined confidence in the capacity of the PNG Department of Health to administer Global Fund grants. And wealthy nations, including Australia, continually review their capacity to invest in international aid according to domestic budgets, priorities and pressures.

For a minute, quite early on in the hospital phase of my treatment, I imagined that at least I might now claim a bona-fide affinity with the people I so often write about. Michael Leunig has a prayer called Blessing In Disguise in which he gives thanks for the common cold: “Nature has entered into them; Has led them aside and gently lain them low to contemplate life from the wayside; to consider human frailty; to receive the deep and dreamy messages of fever … the insights of this humble perspective”.

But TB is not a cold. The neon-flashing revelation, when it comes, is that by virtue of sickness I am now further removed from the wayside of The Corners than ever. Some 95 per cent of TB deaths occur in low- and middle-income countries.

I’m the most privileged TB sufferer in my wide acquaintance – an otherwise healthy white woman in a wealthy country, attended by a small army of specialists and devoted carers, with unfettered, unbilled access to expensive, albeit frighteningly toxic, pharmaceuticals.

Not once do I contemplate having to confront the obstacles and agonies endured by TB patients I have met in places like Daru. Indeed, all being well, the worst consequence for me will be life interrupted, a spanner thrown into plans for work and travel. I am not one of the fevered, long-suffering patients I have seen wilt and expire while they wait for treatment.

I may have fluffed the getaway. But I was born with my ticket out.

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56 COMMENTS ON THIS STORY

by Garry

This article is an absolute credit to Jo's humanity and her sense of professional responsibility. She writes compellingly, without forcing her audience to drink. Best wishes!

January 6, 2014 @ 12:33pm

by Helen McCarthy

Jo, Thankyou for 'sharing' your terrible story & illuminating the difference between yours & the tragic plight of so many in PNG. We in Australia must help . Best wishes for your recovery.

January 11, 2014 @ 4:19am

by Mathalin Barton

What a brilliant read. I am a Papua New Guinean residing in Melbourne and thank you for sharing my people's plight. At this very point in time, I am grieving the loss of my nephew, aged 26, and my niece's 12 year old son who passed away within a space of a week from TB Meningitis. I am sad but angry at the same time that Government, with all the money from the resources boom, inject into fighting TB and setting up the Port Moresby General Hospital with equipment and medication that can save the lives of everyday Papua New Guineans who cannot afford private hospital fees. I will find a way to help with TB in PNG as it has taken two of my family members. Thank you, once again.

February 4, 2014 @ 10:46am