Directly observed therapy

Padmasayee Papineni

> "it was all about standing alone
> in a big grey city
> and somebody suddenly
> handing you marigolds"
>
> *The Lift (2013), Janis Freegard*

A damp patch above Daljit's bed had slowly spread across the ceiling, turning yellow, then brown. In the depth of winter, he wore two pairs of socks, a jumper, and his coat to bed. A puff of vapour appeared each time he exhaled. He shared the bedroom with five other men. There was no window to throw open to ventilate the room with fresh, crisp air and odours lingered. Daljit continued his work in construction, despite his wet, hacking cough. His previously muscular arms had been replaced by the twigs of a bare winter tree and he struggled to lift the bricks. As the apartment block he was building grew taller and shinier on the skyscape of this ever-expanding city, his body diminished.

When he had coughed that morning, the contrast of the crimson haemoptysis against the white of the sink basin had startled him. Dark circles under his eyes betrayed the nocturnal rattling cough that disturbs his rest. There was so little subcutaneous fat covering his skeleton that his clavicles jutted out and his ribs protruded. The sputum smear was positive. I explained the diagnosis of tuberculosis and the treatment. I repeated phrases that I had said many times before: "it is very important that you take the medications every day", "tuberculosis is curable", and "tuberculosis care and treatment are free". Daljit asked me the question that matters most to him: "Doctor ma'am, when can I work?" The diagnosis of tuberculosis meant Daljit's landlord and boss did not allow him to return to work or his room. There was no job contract and no rental agreement. Daljit paid cash weekly to the landlord, and without work, he had no money for rent. One of Daljit's roommates packed his possessions and dropped them off at the hospital—a lifetime of belongings fitted into a small carry-on suitcase. An overstayed visa and therefore no recourse to public funds meant endless paperwork for our tuberculosis team to secure a hostel bed for Daljit.

Ahmed, our hospital's tuberculosis outreach support worker, now visits Daljit in his hostel and watches him swallow the tuberculosis medications daily. Daljit has no savings. All the money from his job was sent home to his wife and children in India. Ahmed shows Daljit how to access the *langar* (community kitchen) at the local gurdwara to get his meals. The *langar* is run by Sikh community volunteers. Early each morning before the sun rises, elder Punjabi women knead and roll dough to make the chapatis that Daljit eats with dahl. A month passes. Daljit gains weight and strength and finds another construction job. Cash is paid directly into Daljit's hands, to cross seas and lands to fill his children's stomachs and futures.

The patients Ahmed supports are socially vulnerable and have complex needs. Ahmed visits Patrick in his apartment to watch him swallow his tuberculosis medications. A year ago, tuberculosis pericarditis had squeezed Patrick's heart, requiring emergency drainage, and tiny ring-shaped tuberculomas had developed in his brain. Empty bottles of vodka and crumpled beer cans are strewn around the room and Patrick sits slumped in front of the television. Ahmed takes a black bin bag and clears the surfaces of the debris. The refrigerator is empty apart from a loaf of mouldy bread, a green fuzz creeping across its surface. The next day, Ahmed brings Patrick a bag of groceries filled with fresh fruits, milk, and bread. Patrick swallows his tuberculosis medications and takes a gulp of beer to wash them down. He tells Ahmed that if he stops drinking completely the shakes and sweats and spiders crawling all over his body will come.

Ahmed accompanies Patrick on the bus to his clinic appointment. The recent MRI shows the tuberculomas have resolved and I am pleased to report to the public health authorities that he has completed treatment. The MRI had also revealed Patrick's shrunken brain from decades of alcohol use. He promises again to attend sessions at the community addiction clinic. A year of treatment is complete and our team say our farewells to Patrick, with the unsaid awareness that if the tight grasp of alcoholism continues, an early death is likely.

November is the most miserable of months in the UK. No sunrise emerges from the dark and icy morning to bring light to the day. Ahmed visits the park to watch Dhillon swallow his tuberculosis medications daily.

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Department of Infectious Diseases, Ealing Hospital, London North West University Healthcare NHS Trust, London UB1 3HW, UK (P Papineni FRCP)

Correspondence to:
Department of Infectious Diseases, Ealing Hospital, London North West University Healthcare NHS Trust, Southall, London UB1 3HW, UK
p.papineni1@nhs.net

Their meeting place is the third bench after the entrance gate. Dhillon's lungs were almost obliterated by the combination of tuberculosis and years of smoking heroin and street living. Ahmed has a flask of hot *shaah*, Somali spiced tea with milk, and pours a mug for Dhillon. Dhillon's fingers clasp the mug, finding comfort in its heat. Dhillon smiles at Ahmed, the few teeth remaining in his mouth brown with decay. Dhillon holds a pizza box he had found in the bins in the alleyway behind a row of restaurants. Grease soaks through the square cardboard box and with a few mouthfuls of an already half-eaten pizza Dhillon's burning epigastric hunger pangs wane. Dhillon's usual sleeping spot is under the railway arches, offering some protection from the rain and wind. He has collected cardboard to layer with newspaper to form a makeshift mattress. He shivers himself to sleep and is usually woken by the loud beeping of a garbage truck reversing, his alarm clock to meet Ahmed and swallow his tuberculosis medications.

Other patients our team supports face different challenges. Aisha had put the back pain down to sitting for the whole day in a cramped lecture theatre and evening shifts standing in the food packing factory. She took increasing capsules of ibuprofen to get through daily life. Aisha could not miss any of her university lectures; her parents had dug themselves into a trench of debt to pay for her education. An excruciating stabbing pain in her back and bedclothes soaked with sweat disturb Aisha's sleep. As I examined Aisha's spine, she cried out in pain when I palpated a kyphosis of the thoracic spine, the gibbus deformity from the destruction and collapse of a vertebral body. Treatment is started and a brace provided to hold Aisha's spine still. The diagnosis of spinal tuberculosis remains hidden from Aisha's parents; she refuses to cause them the anxiety of an unwell child thousands of miles away and alone, and instead fakes stories of her happiness in telephone calls with her mother. Without the factory work, Aisha's money does not stretch far enough to cover the bus fare to the hospital and food. Ahmed visits Aisha to watch her swallow the medications. The tuberculosis nurses have reached into their pockets and pooled together some cash that Ahmed gives to her for some relief from the financial strain of keeping her body nourished and staying alive.

Directly observed treatment for tuberculosis involves a health-care worker, or other trained community member, watching as an individual takes their medication. The aim of this form of drug administration is to promote adherence by ensuring that the person takes all prescribed medications and to monitor the response to treatment. Directly observed therapy is considered an integral part of enhanced case management for individuals with tuberculosis from underserved groups. However, as Professor of Sociology Paul Draus comments: "One might [...] wonder why any adult would need to be *watched* in order to properly take the medicine that they need to save their lives and protect those around them". The original public health control strategy of tuberculosis care that included directly observed treatment as just one aspect of managing tuberculosis was hijacked by the paternalistic concept of watching adults swallow tablets. As clinicians, we ask our patients to trust us with their health and then suggest directly observed treatment, tipping the scale so the imbalance of power lies firmly with us. The control no longer relates to tuberculosis in the community, but control of the individual. Despite endorsement by WHO, if clinicians follow the evidence, directly observed treatment does not provide a solution to the challenge of adherence. Our patients' stories reflect that the barrier to adherence and getting through tuberculosis treatment is the pain of poverty and the absence of a social safety net. Yet across the globe, thousands of people with tuberculosis are watched as they swallow tablets each day.

Tuberculosis consumes bodies and interrupts lives. Health professionals prescribe tuberculosis treatment on charts, but cure is only possible if the medications are combined with sensitivity to the suffering of others. Directly observed therapy is not merely the act of witnessing tablets being swallowed. It is a treatment approach that shows compassion and respect, and recognises the basic human needs of food and warmth. Directly observed therapy is standing alone in a big, grey city, and someone handing you a cup of hot *shaah* on a cold day.

Declaration of interests
I am a Consultant in Infectious Diseases and Acute Medicine and the clinical lead for tuberculosis at London North West University Healthcare NHS Trust and declare no other competing interests. Patients' names and details in this essay have been changed out of respect for patient privacy. The colleague mentioned in this essay has given his permission to be named. The quote from *The Lift* (2013) by Janis Freegard is reproduced with the permission of Janis Freegard. https://janisfreegard.com/2013/08/16/a- poem-for-national-poetry-day/©Janis Freegard.

Further reading
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