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Reflections on the illness experience of a family physician

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Tuberculosis is such a part of our everyday lives that I have never stopped to consider the illness experience regularly lived by our patients. As a seasoned family physician in public service, I have initiated hundreds of patients on tuberculosis treatment, simply informing them of their diagnosis and advising them to go to the clinic to obtain their medication. Even with the use of a patient-centred approach and shared decision-making, I did not give much thought to understanding the implications of how this diagnosis impacts on a patient's life. That was until I was faced with tuberculosis myself.

Keywords: healthcare worker, illness experience, reflections, tuberculosis

Background

South Africa is ranked third of all countries with a high tuberculosis burden, with 0.40–0.59 million incident cases in 2010, outranked only by India and China.¹ The country has shown an increasing trend with regard to new cases. The latest tuberculosis incidence is estimated to be 1 170 per 100 000 of the population (2013 figures).²

It is well-recognised that globally, healthcare workers have an increased risk of contracting tuberculosis because of occupational exposure to the tubercle bacilli.^{3–5} A 2003 review of 51 studies which summarised the burden of tuberculosis in healthcare workers in low- and middle-income countries found the prevalence of latent tuberculosis infection in healthcare workers to be 54% (range 33–79%), with a positive association with increasing age and duration of employment in a healthcare facility.⁵ Latent tuberculosis infection incidence was measured in six studies which showed an annual risk of infection ranging from 3.9–14.3%. The attributable risk fraction from occupational exposure ranged from 2.6–11.3%.⁵

A 2006 study on staff from eight regional hospitals in KwaZulu-Natal demonstrated a median incidence of tuberculosis of 1 133 per 100 000 in healthcare workers.⁶ This study reported poor treatment outcomes, in which only 41% of tuberculosis cases completed treatment.⁶ The Western Cape provincial figures also indicate that an increasing number of healthcare workers have received workers' compensation for tuberculosis (Figure 1). Despite evidence of under-reporting, pulmonary tuberculosis is the third most frequently reported occupational disease in South Africa.⁷ [Below follows a narrative of the illness experience of the first author \(RS\), with support and supervision by the second author \(LJ\):](#)

My experience

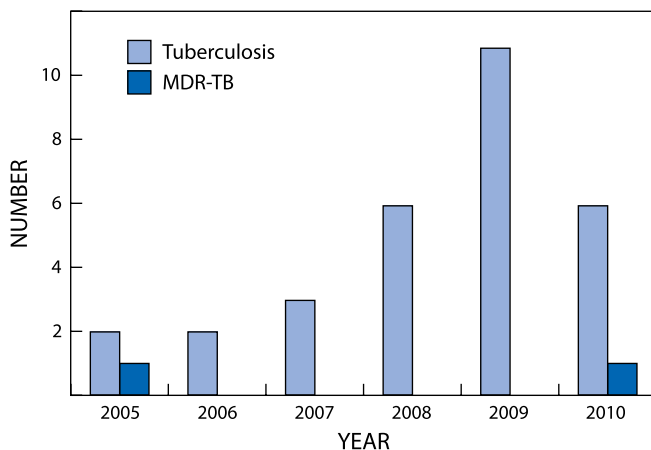
I am an avid runner, and in October 2012, had a goal of running a half marathon. The training was going well, except that I had a dry cough following a bout of influenza in June. I self-diagnosed an acute exacerbation of my asthma due to the recent influenza, and increased my dose of inhalers without further thought. Training continued according to schedule. When I started to have a localised area of wheeze which I could feel and hear in my left upper lobe, I became concerned. My general practitioner prescribed a course of high-dose antibiotics, without effect. In August, a chest X-ray showed a full left hilum. A physician

suggested that I send a sputum for GeneXpert® *Mycobacterium tuberculosis*/resistance to rifampicin and culture, take a course of prednisone to alleviate my asthma, and undergo a repeat X-ray in six weeks. As my cough was dry, I did not manage to produce sputum, even with the help of physiotherapy.

Eight weeks later, with no improvement in my cough, no sputum and new symptoms of chest pain and extreme fatigue which I thought were due to a heavy work schedule and training for my race, a repeat X-ray once again showed a full left hilum, and also fibrosis in the left upper lobe and tenting of the left diaphragm. A radiologist requested a computerised tomography scan of my chest, which was suggestive of tuberculosis, and so a bronchoscopy was carried out to obtain a sample in order to make the diagnosis. Finally, I had a diagnosis and could start my treatment. By this time, I was so weak and frail I could hardly walk five steps without assistance. I joined the queue of regular patients in the local clinic to obtain my medicine, and so my six-month journey began. My mother flew down from Botswana to care for me for two months as I literally couldn't do anything for myself. The professional became a patient.

Some of the darkest days of my life were the first few weeks of treatment. I vomited every day. I had lost five kilograms before the diagnosis was made, and a further seven due to the toxic effects of the treatment. My liver function became deranged, and the pyrazinamide was stopped for a while. It was a struggle to get every spoonful of food in. I had a fever that would not subside, and I was afraid to breathe too deeply in case it triggered a coughing fit, which, in turn, would make me vomit. I developed a skin rash from the medication and had severe body aches. I lay in my bed shivering, focusing on every breath, forcing any food that I had managed to get in to stay down. Even talking was too much of an effort. All I wanted was to get well. I was doing everything that I could to get better, and taking my pills as prescribed, as well as vitamins. I couldn't understand why my body was taking so long to heal, and was despondent at my slow recovery.

I experienced many emotions. I felt betrayed by my own body. Numerous healthcare workers are exposed to tuberculosis. Why had I fallen ill? I was frail, vulnerable and alone. Being in isolation didn't help the loneliness. Even after I was considered to be non-infectious, some people continued to avoid me, increasing



MDR-TB: antitubercular resistant tuberculosis

Figure 1: Trends in the number of tuberculosis and multidrug-resistant tuberculosis cases compensated by the Western Cape Department of Health from 2005–2010

my sense of isolation. I was enraged at the hospital system and the patients who had exposed me to this disease. I was angry at myself for not taking better care of myself. I was furious at my colleagues for not diagnosing me sooner. I was incensed at the pressure I was feeling to return to work, even though I was incensed too ill to contemplate it. Why was my body taking so long to respond to treatment? I felt guilty that I was not at work, carrying my share of the load, guilty that I had ignored my own symptoms and allowed the disease to progress so far, guilty for exposing my friends and family to this potentially lethal disease, and I was really frightened every time I heard that one of them had a cough or cold. Perhaps I had infected them.

However, I was also grateful that I had drug-sensitive tuberculosis, family support, friends who encouraged me and an amazing doctor who cared for me, even sending his wife to draw blood from me in my own home when I was too weak to go to the clinic or hospital. I was humbled during this time. People who I did not know sent me parcels and get well wishes. Prayer groups across the country were praying for me. I was also grateful to God for this time of forced reflection and re-evaluation, and for the restoration that took place.

It took eight weeks before I could keep food down. Even six months after my treatment began, I became nauseous much more easily than I had previously. After being bedridden for six weeks, I started to walk again. At first, a flight of steps was too much. Slowly, I progressed to walking a block, then two, and finally I could walk for approximately 30 minutes. Going back to work was difficult. I was exhausted. I would return home and sleep for the rest of the day. The health service was unwilling to let me work half days or overtime for half the time, except

during the first week. I felt alienated by the fact that I had been away for so long. Colleagues were unsure as to how to treat me. It felt as if some of them resented my long absence.

What did I learn from my illness experience? What would be of value to others?

I gained new insight into and empathy for the plight of patients, particularly those with a chronic disease. I have a deeper understanding of the illness experience of patients, which has led to a deeper level of humility, empathy and patience for patients during shared decision-making around treatment. The value of a support system, consisting of loving carers, and family and friends, cannot be overestimated. Now, I have a more balanced approach to my work, and I make time for relaxation and rest. Patients face the same struggle when taking their treatment and need to be encouraged to do this. It is quite understandable why patients default with their treatment. The sense of stigma, alienation, hopelessness, guilt and fear that they experience when confronted with a diagnosis of tuberculosis needs to be appreciated by healthcare workers. The complexity of this disease hit me in my gut and soul. It affects the whole person, his or her family and patients with tuberculosis need a comprehensive, biopsychosocial approach, well described by the late George Engel.⁸

At the time of writing this, my diagnosis was made over a year ago. I can triumphantly say that I survived tuberculosis! I am back to running half marathons, despite the fibrosis. My lung function is 100%. I have gained seven of the 12 kg that I lost. Work continues as normal, but I will never be the same. There is something that changes when you go through a trial like this; a transformation of mind and spirit – growth – for which I am grateful.

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